

✓

LIFE HISTORIES OF PEOPLE WHO STUTTER:
On Becoming Someone

HARSHA KATHARD

**Dissertation submitted
in
fulfilment of the
requirements for the degree:**

**DOCTOR OF EDUCATION
In the School of Education,
Faculty of Humanities
University of Durban-Westville**

***Promoters: Dr. Michael Samuel
Dr. Vijay Reddy***

March 2003

Student Number: 8218320

ABSTRACT

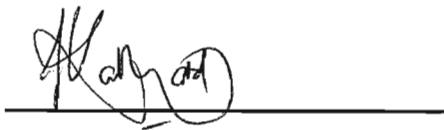
This study explores participants' experiences of stuttering in their lifeworlds over time through the lens of self-identity formations. The critical questions raised are: How do participants form their self-identities in their lifeworlds over time in relation to stuttering? In the context of their self-identity formations, how do they negotiate stuttering? A narrative life history methodology was used with intention to access personal, temporal and social dimensions of experience. Seven adult participants, two female and five male participants, with histories of living with stuttering since childhood, were invited to share their stories. Their personal experiences are embedded in diverse lifeworlds in KwaZulu-Natal, South Africa, a context making a sociopolitical transition from apartheid to democracy. The data was produced through retrospective accounts of their experiences via a series of dialogical interviews. Issues of empathy, power, and positioning and quality in the research process are problematised. The data was analysed at three levels. The first level of analysis entailed a narrative analysis of interview data, represented as seven individual research stories. The second level of analysis is a cross-case analysis using the seven research stories for the purposes of theorising. The outcomes of the third level of analysis are abstractions and explanatory concepts which respond to the critical questions in a general way.

The genesis of two self-identity trajectories, self-identity as DisOther and self-identity as Able/Potential are traced over time. The biographical, contextual and social forces shaping self-identity formations and participants' actions in negotiating stuttering are illuminated. The self-identity trajectories are unique in the context of each biography. However, the relative prominence of self-identity formation as DisOther across cases in school years was evident. In contrast, self-identity as Able/Potential became prominent, during adulthood, for some participants. The experience is rendered as complex and fluid through a set of abstractions and explanatory concepts. These concepts foreground the changing and multiple relationships between self-identity formations, the influence of social forces shaping self-identity, the impact critical catalysts shaping self-identity formations, and strategic manipulation of self-identity in negotiating stuttering. In particular, the strategies to negotiate stuttering successfully are examined. The limitations of the study and potential application of this theoretical offering in the research, educational and clinical domains of Speech-Language Pathology are discussed.

DISCLAIMER

I hereby declare that this thesis is my original work and has not been submitted before to any other institution for assessment purposes.

Further, I have acknowledged all sources used and cited these in the bibliography.

A handwritten signature in black ink, appearing to read 'H. Khan', is written over a horizontal line.

Researcher

Promoter

DEDICATION

**FOR MY PARENTS,
KAMLA and MOTH KATHARD**

My Storytellers

ACKNOWLEDGEMENTS

I acknowledge the following people who made this project possible:

Participants in this project, who generously shared their stories with me. I will cherish these stories because they have re-educated me in a profound way.

Mershen Pillay, a brilliant mind, and a rare friend. This thesis was a truly dialogically – fashioned experience. We had intense discussions - on aeroplanes, in corridors, at seminars. He dragged me through the difficult debates even when I stubbornly resisted, and forced me to see the world in different ways.

Ruth Beecham, my colleague and friend, who spent many hours with me sharing experiences, expertise, joys and perils of life history research. She understood my personal struggles and fully appreciated why my research story needed to be told.

My conversational partners, readers, friends – Sandhya (Chetty), Farhana and Penny. A unique blend of astute minds who read, talked and shared their ideas with me. I was in good company because they were fighting similar battles in the classroom, clinic and in research.

My Promoters, Michael Samuel and Vijay Reddy, a dynamic duo. An artist and scientist. A special combination of exceptional talent who provided a space for me to explore, create, analyse, challenge, change and question. Together, they sharpened my ways of seeing.

Renuka Vithal, my mentor. At our many doctoral seminars she shared her intense passion for research which was infectious. She reminded me of my privileged position as a researcher in South Africa, of the moral responsibility I had in creating knowledge; that research was not an innocent process; and that we should not produce knowledge that subordinates. Her voice still rings in my head ... that is why I have used the word “problematise” so many times here.

Legini, Neethie, Sandhya (Singh), Seema, Serela, Sheena, Daisy, Rubby, Daryl, Alan, Farida, Labby, Roshnie, Kgomotso and Richard with whom I spent many hours - talking, learning, grumbling, sharing, comforting. They understood and lightened my load.

Razia Patel and Shireen Govender, for the endless hours of careful transcriptions.

Connie Israel, for meticulous editing.

Gloria Fikele Ngcobo, for keeping the domestic routines going, quietly and efficiently.

Haile Gerima, for providing the inspiration to tell my story.

Sanusha Jugoo, a very special person, for working diligently on the reference list for many hours.

Prem Rughubar, my mother-in law, for her constant support, understanding, babysitting, and for believing that women should be educated.

Kamla and Mothi Kathard, my parents, for a lifetime of love, pots of food and countless hours of baby sitting, for encouraging me to Become Someone.

Rayan, Riya and Rivan, my precious family.

Rayan, my husband, for being my willing partner through this journey. He spent many, many hours driving me to interviews, around the country for references, helping with printing, photocopying, compiling reference lists, formatting the document; keeping me company through the difficult times; and loving me, always.

Riya, my daughter, for allowing me to turn her bedroom into an office for three years, reminding me to eat and sleep, and waiting patiently for me to complete this project so she could have mum back again.

Rivan, my son, for an abundant supply of sweet smiles, hugs and kisses.

The National Research Foundation, for supporting this project (2001-2003) through the part-time Doctoral Scholarship Programme, Social Sciences.

THANK YOU.

TABLE OF CONTENTS

Preface	i
Chapter One: Introduction and Rationale	1
1.1 Introduction	2
1.2 Rationale for the Study	3
1.2.1 Life world experiences and clinical practice concerns	3
1.2.2 New imperatives for practice	10
1.2.3 Knowledge Productions Concerns	13
1.2.4 Experience as data in stuttering research: Contributions, gaps and silences	26
Chapter Two: Literature Review and Theoretical Landscape	31
2.1 Life experience research in medical disciplines	33
2.1.1 Experience as a thoroughfare: body, Self and society	35
2.2 Theorising Self-Identity formation	46
2.3 Self-Identity and social action	57
Chapter Three: Situating Life History Research Methodology	60
3.1 Introducing life history methodology	60
3.2 Narrative: A legitimate way of knowing	63
3.3 Life history - A suitable methodology for exploring self-identity formation	67
3.4 Producing data through dialogue	70
3.5 Problematising methodological concerns	73
3.5.1 Life history research, relationships and positionality	73
3.5.2 Not innocent: Ethics & Politics	74
3.5.3 Problematising narrative research methodology with PWS	75
3.5.4 Memory and life history	76
Chapter Four: Methodology: Issues & Choices	80
4.1 Pilot Phase	81

4.2 Inviting Participation	84
4.3 Initial contacts	89
4.4 Research Instruments	91
4.4.1 Interview schedules	91
4.4.2 Understanding Myself: Researcher-as-Instrument	91
4.5 The Interview Process	93
4.5.1 Developing the research relationship	93
4.5.2 Conducting an interpretive conversation: sensing and connecting	96
4.5.3 Power in the research relationship	99
4.5.4 How the interviews unfolded	100
4.5.5 Memo-writing in the research process	101
4.6 Generation of Transcripts	101
4.7 Analysis: Guiding Theoretical influences	102
4.8 First level analysis	105
4.9 Second and Third level analysis: Generating theory from research stories	115
4.10 Substantive Validating	118
4.10.1 Methodological choice	118
4.10.2 Credibility: How does one demonstrate that the research is credible?	118
4.10.3 Procedural Dependability: Auditing	121
4.11 Ethical validating	122
4.11.1 Nothing is innocent: Maintaining moral responsibility	122
4.11.2 Generative Promise	124
4.11.3 Practical value	124
4.11.4 Transformative potential	125
Chapter Five: Research Stories	127
Siyanda's Story: Too good to be true?	128
Kumari's Story: Building yourself inside-out	140
Gareth's Story: A long journey	151
Sagren's Story: Re-invent yourself	167
Thabo's Story: A Terrible Struggle	177

Hennie's Story: Packaging and Presentation	186
Nontokozo's Story: Little Hiccup, BIG problem	196
Chapter Six: Analysis of life history data	202
6.1 Early Years (0-6 years): Variable beginnings	204
6.2 School Years: Multiple routes, forces and actions	208
6.2.1 Primary School Years: (6-12 years)	208
6.2.2 High School Years: (12-18 years)	216
6.3 Post-School Years	224
6.3.1 On Becoming Someone: Strengthening and foregrounding self-identity as Able/Potential	224
6.3.2 Foregrounding self-identity as DisOther in adulthood	237
Chapter Seven: Abstractions and Explanatory constructs	241
7.1 Relationships between self-identity trajectories over time	242
7.2 Critical catalysts, crucial choices and changes over time	244
7.3 Social context and the shaping of experience	246
7.4 Conforming and transgressive stances	248
7.4.1 Grander Purpose in life and imagining possibilities	249
7.4.2 Enabling ideologies for Self-reflexivity	250
7.4.3 Resourcing and Actioning	251
7.4.4 Challenging, protesting, dialoguing	251
7.4.5 Reconciling competing self identities	252
7. 5 Concluding Comment	253
Chapter Eight: Reflections, Limitations, Implications	255
8.1 Research Process	256
8.2 Clinical Practice Implications	267
8.3 Educational Implications	281
References	285

LIST OF FIGURES AND TABLES

	Page
Table 1: Contrasting Positions of Medical and Social models to Disability	10
Table 2: Biographical profiles of participants	88
Figure 1: Thematic emphasis in stuttering research	20
Figure 2: Interactions: Levels of Analysis, Theoretical Influences and Outcomes	105
Figure 3: Genesis of Self-identity as DisOther	223
Figure 4: Genesis of Self-identity as Able/Potential	235
Figure 5: Summary of abstractions and explanatory concepts	241
Figure 6: Multiple Relationships between Self-identities: Able/Potential and DisOther	242

LIST OF APPENDICES

APPENDIX A:	Sample Diagnostic Report and Commentary
APPENDIX B:	Sample Treatment Plan and Commentary
APPENDIX C:	Pilot Phase Reflections
APPENDIX D:	Guidelines for Participants for the initial interview
APPENDIX E:	Consent Form: Sample
APPENDIX F:	Interview Schedules
APPENDIX G:	Scheduling of Events
APPENDIX H:	Memo-writing sample: Interview Process
APPENDIX I:	Sample of Interview Transcript
APPENDIX J:	Diagrams: Levels of Interpretation and Metatheory
APPENDIX K:	Discourse Analysis Framework
APPENDIX L:	Story review Guidelines for Participants
APPENDIX M:	Memo-writing: Data representation and Analysis
APPENDIX N:	Sample of Individual Case Analysis
APPENDIX O:	Memo-writing sample: Research story review and analysis
APPENDIX P:	Online Conference Transcript
APPENDIX Q:	Personal experiences of the phenomenon of stuttering

NOTES ON TERMINOLOGY AND ABBREVIATIONS

People Who Stutter (PWS): I use the term People Who Stutter (PWS) noting that this term is problematic because it “labels” the individual by his stutter. In the absence of a more suitable option, I retain the term. The term “stutterer” is commonly used in the literature but was not appropriate in the context of this study. However, I use the term “stutterer” where intended by the authors in the literature.

People with Disability (PWD): I use the term noting that it is not an ideal term for reasons discussed above.

Clinician: I use the term clinician because it is commonly used in KwaZulu-Natal to refer to the Speech-Language Pathologist in the clinical settings. The terms vary across practice contexts. Speech therapist, speech-language pathologist, and practitioner are also used.

Client: In the profession of Speech-Language Pathology in South Africa, terminology changed from patient to “client” in the late 1980s. It was argued that the term “patient” conveyed the impression of one who was sick and the people who came to the clinic had disorders and were frequently seen outside of hospital context. It was also an era influenced by consumerism and the person seeking therapy was regarded as the “client” and the “clinician” was the service provider. For these reasons the term changed from “patient” to “client” although they continue to be used interchangeably in some contexts. In this document I use the term client.

Use of pronouns: I used the term “him” as a collective term for PWS since the majority of clients at the clinic are male and there is a 3:1 ratio of male to female PWS.

“She” is used to refer to the clinicians. The majority of clinicians in the Speech-language Pathology profession are female.

PREFACE

A story occurs in the midst of other stories

I attended the launch of the Film Festival, a part of the World Conference Against Racism, on 29 August 2001, Durban, and wrote this piece immediately thereafter. I was inspired by the words of Haile Gerima, an Ethiopian representative of the international film community. He spoke spontaneously, from the heart. As he spoke I found myself scrambling for a piece of paper to write what he was saying because his words resonated with my experience as a researcher in South Africa. I was mesmerised by what he said of being kidnapped by cultural imperialism, of the need to tell stories that reconstruct who we are, of how cultural subordination takes place even when intentions are good, and of the cultural diet we have been fed in oppressive societies. "Tell your story," he pleaded, "if you want to deliver your own freedom". Here is my research story.

A story always occurs in the midst of other stories. My research story, which I present here as an academic piece, can only be fully appreciated when understood as part of my personal story. Why did I choose to understand the life histories of People Who Stutter (PWS)? My concerns began in the clinic as a professional speech-language therapist. A brief historical contextualisation of my professional career is necessary here. I have been a student, and a speech-language-hearing clinician in South Africa, for a period of 20 years (between 1982-2002). During this time I have had numerous theory-practice concerns. In this study I raise a single but central concern: my concern about the need to understand the lifeworld experiences of people I work with, in this instance the People Who Stutter (PWS).

As a South African university-student of Indian descent (1982-1986), and a child reared in an apartheid society, I was uncritically socialised into an imported Western, medical model of practice during my professional training. The powerful and seemingly "neutral" professional knowledge created in the West and delivered via a transmission model of education did not seem to encourage questioning and self-reflection. As a learner, I imbibed knowledge and unquestionable facts that took precedence over my (different) ways of knowing the world. The written text held ultimate authority. In such a context it was difficult for me to reconcile what was going on inside the classroom with the outside. During this period, in the 1980s, the country was in the midst of the struggle against apartheid. Yet these social realities

did not enter the speech-language pathology classroom. I still try to fathom why I initially did not question why 80% of the country's population did not receive any of our professional services, why there were no Black speech therapists, why we did therapy in English only. Was this because apartheid dictated the norm? Was it because our profession pretended to be *apolitical, sanitised and acontextual*, immune to the realities of life and was, in fact, promoting a strong Western, medical ideology as a naturalised practice? Was it because we pretended to live very normally in a very abnormal society?

When I began to practise in KwaZulu-Natal in 1986, Speech-Language Pathology was new and unknown as a profession for the majority of the people in the province, given the historic maldistribution of clinical services in an apartheid-ravaged South Africa. As a new graduate I was determined to uphold and promote the interests of the profession. My practice in the first ten years was shaped by apartheid which privileged service delivery to middle-class, White and Indian, monolingual, English speakers. The early years of my practice proceeded in a seemingly unproblematic way. I was the professional, an expert, and able to help those who stuttered. Upon qualification I religiously enacted the rituals of the profession's cultural practice and taught it to my students as if it were the ultimate truth, becoming a ventriloquist for an uncritical professional practice.

In my typical clinical practice routine the person enters the clinical environment and is constituted as a stutterer, a client. I simultaneously occupy the role of clinician. My task in the clinical assessment seeks to characterise the nature of stuttering (the disorder) using formal and informal procedures. Measures of frequency, severity and attitudinal dimensions of the disorder are taken. Based on the assessment outcomes, a treatment regime is recommended for the client. The treatment/management process involves interacting with the client for the purposes of developing a (clinical) relationship to change attitudes, speech behaviour and feelings regarding stuttering and communication using fluency-shaping (changing speech patterns) or stuttering modification (modifying the moment of stuttering and fostering adjustment to stuttering) programmes. The outcomes of therapy are typically measured by reviewing the reduction in the number of disfluencies and measuring changes in attitudes towards communication.

Initially, my practice was unproblematic to me because it offered some degree of certainty as I conformed to the rituals of practice as a new professional. However,

over time anxieties began to creep in as I began to reflect (silently and secretly) on my practice. A public declaration of my clinical anxieties would have been dangerous. Professionals had to be certain about their knowledge and practice. My ambivalence and uncertainty could easily be interpreted lacking as competence. I began questioning the purpose of the clinical engagement. Was it to treat the client? Was it to care for him? Was it to help/empower him? To make him normal? Perhaps all of these. I wasn't sure. These were philosophical issues that have historically demanded debate but did not feature in my contexts. I didn't have answers to questions that were central to every action I take with PWS. My anxieties were amplified because I was also a clinical educator/lecturer and had to teach students about a practice I was seriously questioning and doubting.

There were many issues central to my discomfort:

I questioned the identities and power imbalances between the client and myself within the clinical relationship. As we took up our respective positions, myself as professional, knowledgeable *expert* and him as client, there was a resultant *power imbalance*. A typical doctor-patient relationship. I knew that my purpose was altruistically motivated and that I had to work *with* the patient especially because my practice was mostly *talk-based*. I did not offer any medication or technology to treat the problem. However, the talk was mainly *my* expert talk about *disorder*. The same applied to the client. In a Parsonian tradition (Turner, 1999), the patient is expected to act according to the normative expectations of a sick role and relies on the professional to chart the course of treatment as he passively receives treatment. In my experience the client was most often willing to follow the treatment regime of the expert professional. I do not have a problem with specialised knowledge but I felt that this knowledge alone was not enough and far from useful, adding to my discomfort.

I was not just a professional. I was also a mother, wife, daughter, friend, Indian, female. However, a consequence of a fixed, singular positioning of myself as clinician was that I denied entry of "useful" knowledge based on my life experiences. This knowledge was not professionally acquired and often ran contrary to my thinking as professional. As full-blooded, active, human beings, we were obliterated. Neither the client nor the clinician were "real" people in this relationship. In fact, I seemed to be witnessing our "collective absences".

Within the structure of this professional relationship, my therapy methodologies were intended to be interactive and collaborative but the rituals of practice promoted an “objective” stance. This troubled me because I knew that for effective management the PWS had to be a participant. He had to collaborate in the process. He had to take the driver’s seat. I tried to collaborate with the PWS based on what I thought was important. The collaboration was false because I privileged my knowledge from narrowly defined professional boundaries. The net result was that I had effectively excluded the knowledge the PWS gained from his experience of living with stuttering and issues of importance to him. As a consequence the social and emotive dimensions received marginal emphasis and yet seemed most important.

As the disorder became central, the person and his lifeworld were marginalised. I knew how to profile the disorder, count and measure disfluencies. I knew how to assess primary and secondary symptoms and the client’s attitudes to his problem. However, many questions remained unanswered. Who is this person? How did he get to be this way? What was his lifeworld like? How did he experience stuttering in his life context? What is it like to live with stuttering? How does he understand stuttering? What are the consequences and impact of stuttering on his life, on a daily basis and over time? How does he manage stuttering on a daily basis? How do people in his community respond to stuttering? How does he experience therapy? Why does he use strategies that don’t seem to help? Why did he come to therapy, now? Is he only a person who stutters? Why did he drop out of therapy? Why did he not want therapy? Why didn’t he comply with a particular therapy approach? What strategies does he find useful and why?

I seemed to see only part of the picture. I had a deficit/disorder orientation to my practice. Through my jaundiced eyes I could only see deficit, disorder and pathology as I measured and assessed what he *couldn’t do* in relation to what normal speakers could. But there were the “things that didn’t fit”. Outside of the clinic I met the PWS. They often seemed to be different to how they appeared in the clinic. While they did stutter, some were extremely communicative and successful and shattered the negative stereotypes I held about them. My cousin Katy, who I grew up with, never attended therapy, spoke with a stutter and became a successful store manager. She challenged my own constructions and the textbook assumptions of PWS. I was missing something important. My emphasis on treating or managing the disorder using various treatment approaches often resulted in a failing practice. Despite documenting positive changes in fluency patterns and improved attitudes towards

communication, and recording “success” in clinical reports, I felt like the intervention was not successful. Fluency was short-lived, there was relapse, and I had not attended to the lifeworld issues of PWS. I didn’t understand the person I was working with.

As my practice progressed I let life slip in. I, not just me as professional but me as student, friend, and mother, listened to the stories of PWS and admitted life realities. I opened Pandora’s box. I was extremely destabilised at what emerged. I had no way of understanding the complexity of moral, social, political and ethical human dilemmas. It was a kind of holism I found extremely difficult to comprehend. Panicked, I shut the box. I share the same dilemmas that Hahn (1995) explains in a narrative about a medical specialist who also cut off important questions to a patient: “I’m just damned afraid of opening a Pandora’s (box), and I wouldn’t know how the hell to put the lid back on her, so I just circumvented a lot of areas” (Hahn, 1995: 201). I too, left the box shut, only to peer into it occasionally. But the stories stayed with me. I knew I was missing the plot and it was a grave injustice to those I worked with.

I was in a quandary. My world of work also seemed to be a paradox. I understand stuttering to be a complex, human, multidimensional communication phenomenon. I also understand that working with whole lives and real people is a formidable clinical challenge. Yet despite this understanding, my clinical practice routine remained simplistic and essentialist. I focused on the disorder with marginal attempts at admitting life complexities as part of the clinical process. The therapy was talk-based but there was no real talk. This seemed contradictory - questioning and not knowing on one hand, and yet appearing to know what to do, on the other. I owned the professional knowledge base about stuttering. I was expert. Was I? There was a need for new knowledges, for different knowledges, especially for clinical practice. I waited for many years, frantically reading and searching every journal article and stuttering textbook, which would offer relief. There was little.

Why didn’t I create my own knowledge? There were two reasons. I did not construct myself as researcher or knowledge producer. An oppressive system had led me to believe (incorrectly) that knowledge was produced by expert scientist researchers, by males, with superior skills in laboratories in faraway places. Secondly, I did research only to obtain a Master’s qualification in 1992. The research was confined to the traditions of a positivist, experimental design that offered little relief for issues of

concern to me in the clinic. I remained problematically apathetic about research for a long while. The stories stayed. My silence was no longer defensible.

“Stories are very patient things. They drift about quietly in your soul... They are always successful in the occupation of your spirit” (Okri, 1997: 43,44).

While the stories waited, there was another drama unfolding midway through my career. Our country had made a successful transition to democracy and the voices of challenge were finally being heard. I was inspired by Jonathan Jansen, a charismatic educator, who raised the “standards” debate at many university meetings. In his famous words he questioned: “Whose standards? What standards? In whose interests?”. Together with my colleagues, Mershen Pillay and Ruth Beecham, I began to aggressively question the epistemological and ontological foundations of our professional research, clinical and education practices. Through these interrogations I began to understand why I was experiencing mounting anxieties about my practice. We spent the better part of eight years challenging professional education, clinical practice and research. As Roy (2001) explains “once you see it you can’t unsee it”. I understood the problems clearly and I could not ignore them. I even grew tired of the challenge. We were good at finding the faults but had nothing further to offer. We had to create new knowledges but I was scared. My impression was that conservatism in the profession, and particularly in South Africa, did not encourage such critical practice.

Fortunately, there were many dialogues of change and transformation elsewhere in the country and particularly on our local campus. We were naturally drawn to the conversations in the Faculty of Education at the University of Durban-Westville. Renuka Vithal, Michael Samuel and Jonathan Jansen were the trio who entertained our academic minds within a discourse of possibility. I was instinctively captivated by Michael Samuel’s presentation on potential life history methodology offered in understanding lives in context. This was a methodology I could use to understand those stories which were still waiting, patiently. However, there was a dilemma. I had to find a “temporary” home, a leverage point, in the interests of constructing new and different knowledge. This is how my “Speech Pathology” project became located in Education.

Before I conclude this preface, I must make brief mention about my fascination with stories. I grew up in a family that read, told and taught through stories. I made sense

of the world through stories. The dominant research tradition did not even allow me to think of the possibility that story and research could go together. Now that I have been introduced to the possibility and potentiality of narrative methodology, I embark on a journey into the unknown, with an intention to understand how stuttering is experienced in lifeworld, *through story*. I approach the study with a sense of apprehension because breaking away from a revered canonical tradition of objectivity is no easy task. However, I am also encouraged because I think that we are maturing as a profession, and that there is a willingness to admit an epistemological “Other” in the interests of knowledge construction and methodological diversity. Against this biographical backdrop, I invite you to engage with this academic presentation.

CHAPTER ONE

INTRODUCTION AND RATIONALE

I am swinging in the cellar of our house. My strong arms grip the rope and I pull hard, pumping along with the music from the record player and wearing my favourite red and white striped shirt. Up and back I go, stretching for the low wood ceiling with my feet and feeling the whoosh of the wind whipping past my face. With each pump my heart beats harder and my chest grows bigger until I am bigger than the world. The next thought flashes through me like a lightning bolt. "I will do great things in the world, and other people will know about me." I grab onto it and say it over and over and over to myself, knowing without a doubt that it is true. I am 5 years old and it is 1957, the same year that my kindergarten teacher Mrs. King informs my mother that I stutter.

Ann Mavor, 1998: Mouth Piece

My stuttering and the ways in which my parents dealt with it didn't happen in a social vacuum. My father grew up in the Jewish ghetto of the Lower East side and was educated in New York's public schools. He wanted better for me. I should apply to Harvard, he said. ...I never once talked to him about my stuttering and how inadequate it made me feel...Nor did I talk to my mother about how I felt about going to therapy and not making progress...I never talked about stuttering to my speech therapist ...I see that I was also a victim of the times. Yes I needed help but this was the 1950s ...the "silent fifties" in a personal as well as a political sense...

Humiliation cuts deep. It is often triggered not by an incident of my stuttering but my feeling about being recognised as a stutterer. The shame of being identified and defined by my disability is overwhelming...A humiliating incident can be as trivial as a momentary glance in my direction. As a teenager I went with a friend to see a British comedy "I'm All Right Jack". In one scene, a wizened old trade unionist severely stutters as he tries, incomprehensibly, to articulate his support for the strike. The scene is a cheap shot at rank-and-file trade unionists; they can't effectively articulate a reason for going on strike. What upset me was not the movies' retrograde politics, however. Instead, I felt shame because my friend turned towards me to gauge my reaction as a stutterer in the movie...My response, typical for me, was to steel myself from any show of emotion. ... But I felt naked just the same, as if all efforts to cover up my stuttering problem were stripped away from me. Although I stuttered often in talking to her, I could not tolerate her recognising me and (as I interpreted it) defining me as a person with a stutter. I never spoke to her again after that movie.

For the past thirty years I have lived close to the cutting edge in America. My father's son, I pursued success: if not along the road to affluent suburbia, then certainly on the path of downwardly mobile, countercultural bohemia. As an activist beginning in the 1960s, in the civil rights movements and anti-war movements, as the founder of the best known communal experiments in the country (Total Loss Farm)...I am constantly putting myself forward, taking risks for the ideas and causes I believe in...When the first wave of feminism hit my activist circles in the late 1960's, I was in an interesting position. As one who was scared of speaking in public, I was able to elude the charge of being one of those arrogant men who dominated meetings with self-important speech-making. I also felt the frustration that many women reported experiencing in feeling the pressure from men to keep silent. My disfluent speech put me in a special place from which my own limitations helped me to understand the frustrations and yearnings of others...I won't ignore the political dimensions of empowerment evolved out of the 1960s movements for civil rights and women's liberation, was taken up by gay liberationists and eventually by people with disability, powerfully affecting the way those of us with handicaps saw ourselves...

Marty Jezer (1997) A Life Bound Up in Words.

1.1 Introduction

This study is interested in exploring how (and why) the subjective human experience of stuttering unfolds in the lifeworlds of People Who Stutter in South Africa, over time, and how (and why) stuttering is negotiated. Against the background of my personal experiences in the clinical context presented in the preface and the introductory voices of PWS presented above, I develop the rationale for this study. I begin with an introduction to the study, and present the broad purposes and critical questions before continuing to develop the rationale from an academic standpoint.

The phenomenon of stuttering resists definition. In Speech Pathology literature it is referred to as a speech fluency disorder (Guitar, 1998). Stuttering usually begins in early childhood often between 3-8 years (Guitar, 1998) and varies in presentation interpersonally and intrapersonally across time, and context. Of the 5% of people who begin to stutter in childhood, approximately 1% of the population continue to stutter into adulthood. Although the prevalence of stuttering varies in cultures across the world, it has been observed in communities researched across the world, suggesting that it is “universal” (Bloodstein, 1995; Guitar, 1998). In this study my interest is not with stuttering itself but with the experiences of adults who have lived with stuttering over their life times, a shift in emphasis from stuttering to the person.

Specifically I explore the personal, subjective experiences of stuttering of seven adult participants whose experiences unfold over time in KwaZulu-Natal, South Africa, a context in the process of making sociopolitical transitions from an apartheid society to one of democracy. By using a narrative life history methodology, I generate an understanding of life experiences of stuttering within a research frame that weaves together the personal, social and temporal dimensions of experience. Through retrospective constructions of life histories generated via interviews, I explore how participants experience and negotiate stuttering in their lifeworlds over time.

The primary purpose of this study is to *generate theory* about life experiences (structured around particular critical questions) of stuttering through research stories. The individual research stories serve to illuminate the particulars of each biographical experience, whilst the cross-case analysis forms the basis for analysing and theorising life experiences of stuttering over time. A secondary purpose is to make a contribution to problematising the application of life history methodology within

Speech-Language Pathology, and to the current methodological debates in life history research.

This study explores how *participants experience and negotiate stuttering in their lifeworlds over time*. In the pilot phase of this project it became apparent that in constructing his story, the participant was (per)forming his identities i.e. generating understandings of himself, as a basis for illuminating his experiences of stuttering. The choices he made in negotiating his stuttering were linked to his identity construction: in essence “I act because of who I am”. Against this background it seemed sensible to explore experiences by tracing identity formations and social actions over time. The critical questions are specified as follows:

1. How (and why) do participants form their self-identities in relation to stuttering in their lifeworlds over time?
2. In the context of such self-identity formations: how (and why) do they negotiate stuttering in their lifeworlds over time?

1.2 Rationale for the study

There are two central arguments I make in developing the rationale for this study. I firstly explain that understanding subjective life experiences are important particularly in a clinical practice context and explore reasons for why we are struggling to admit such experiences. I support the argument by discussing the new policy imperatives and context realities which place personal experience central in the ambit of clinical practice. Secondly, I explain my concerns about knowledge production and examine the reasons for the dearth of formal literature about subjective life experiences of stuttering. I also review the few studies which have admitted subjective experiences of stuttering, consider their contributions, and identify the gaps and silences.

1.2.1 Lifeworld experiences and clinical practice concerns

Speech-Language pathologists working with adults who stutter use a diverse range of treatment methodologies. Among the many methodologies, there are those which place life experience as central (DiLollo, Manning, Neimeyer, 2002; Guitar, 1998; Harrison, 1997; Manning, 1996; McDonough & Quesal, 1998; Perkins, 1983; Sheehan, 1975; Van Riper 1973; Williams, 1995). They are among the many

clinicians who maintain an interest in interacting with the multifaceted psychological, emotional, social, historical dimensions of the person's experiences as a basis for managing stuttering. They collectively acknowledge that each individual having lived with stuttering, frequently a stigmatised social phenomenon, has accumulated a lifetime of experience and has developed particular ways of coping in diverse social contexts. In the absence of known cures or quick fix solutions for stuttering, the clinical enterprise therefore requires working with the PWS using a talk-based methodology. In the context of helping the individual, the task of the clinician is to make sense of his story (Manning, 1996) by integrating the complex multifaceted forces shaping the personal experience of stuttering. It is against this background that many clinicians, despite their varying methodologies of practice, place personal experience as central.

As an example, DiLollo, Niemeyer & Manning (2002) have recently advocated a narrative methodology in treating stuttering. They highlight the importance of life experiences in the therapy, seeking to maintain long-term fluency outcomes. Their intention in recommending a narrative methodology in treatment is to understand the role of stuttering in the lives of their clients by deepening an understanding of their life worlds: to explore the issues of stereotypes, emotional stability, honesty in living with stuttering, and to address the development of self-concepts in living with stuttering. These understandings afford the possibility of focussing on the meaningfulness of being a fluent speaker as a basis for the long-term treatment of stuttering and creating lifestyle changes which are conducive to fluency maintenance. In a similar vein, Bloodstein (1993) suggests that adults who stammer present a challenge to the clinician because they bring a lifetime of experiences into the clinical relationship and recommends that interacting with such experience is a prerequisite for intervention. My concern is that while clinicians acknowledge the importance of personal experiences in clinical practice, we lack a supporting empirical and theoretical base to engage with personal experience in a significant way.

Having established that life experiences are important in clinical practice for those who subscribe to such methodologies, I attend to reasons for why we are struggling to place experience as central in clinical practice despite our best intentions. The evidence that clinicians are struggling is reflected in empirical studies in which clinicians have signaled their concerns about their lack of preparedness in working with the social and emotional dimensions of stuttering (Baker, Ross, & Girson, 1997; Cooper & Cooper, 1996; Starkweather, 2001). I remain convinced that there is a

fundamental concern about the nature of clinical practice which has not been explored sufficiently in stuttering and professional literature in general. In my opinion the uncritical application of the medical model in the Speech-Language Pathology profession (henceforth referred to as the profession) has contributed to the *sequestrations of life experience of the PWS at the clinical interface*. I develop my line of argument by exploring the political alignment of the profession, the influences of the time period during which it was established, and by considering how biomedical methodology is operationalised in clinical practice. Furthermore, I provide an analysis of clinical reports in stuttering to illustrate medical influences and draw attention to the current practice dilemmas.

The appropriation of the medical model in Speech-Language-Pathology practice can be understood as a political maneuver by the profession. Historically, the emergent profession has aligned itself with the medical professions by mimicking the rituals of their practice in the clinical, education and research domains. Some scholars argue that the profession chose its practices as a means of establishing its credibility and ensuring its survival (Beecham, 2002; Pillay, 2001b). As a consequence of professionalisation processes in society, the profession has come to hold jurisdiction over knowledge production in stuttering, of educating professionals, and has the responsibility of managing or treating PWS. In a review of the epistemological roots of the profession, Pillay (2003) suggests that when the profession was established in the 1920s within middle-class European and American societies, its intention was to treat people with communication disorders by engaging practice rituals underpinned by medico-centric values. He asserts that speech-language pathologists throughout the world share similar medicalised practice routines, texts and discourses.

The profession was established in an era of technological expansion that became dominant in every area of human endeavour, including medicine. These practice routines were in stark contrast to Western medical practice of the 17th and 18th centuries which attended to the patient's lifestyle, moral stance and environment for its diagnostic and treatment processes (Henderson, 1994). With technological emphasis clinical practice became infused with rational and empirical concerns. In other words, as a response to the powerful influence of positivism, the medical profession fixed its powerful gaze on the disease or disorder (Foucault, 1976), while simultaneously separating disease and disorder from the individual, and the individual from his life world (Turner, 1999). Although practices vary internationally and are shaped by local contextual realities, the core historical-cultural medical

professional practices remain entrenched (Pillay, Kathard, Samuel, 1997; Pillay, 2001b; Kathard, 2002) and powerful.

The profession currently enjoys an official place in a “medical” family and within this reality, stuttering has been formally classified as an “impairment” by the World Health Organisation (WHO, 1999) along with other “medical” conditions. This has not always been the case. Through history, and across cultures stuttering as a phenomenon has received multiple interpretations for centuries (Van Riper, 1973). However, in the Western world in the twentieth century, stuttering has been constructed as a Fluency Disorder because of its professional location. In the ICDH-2, stuttering is listed as an impairment of speech-form that can lead to disability and handicap depending on the individual's personal response to the impairment (WHO, 1999; Yaruss, 1998). It has therefore received formal social meaning as a “disorder” within a context of biomedical classification, along with other medical conditions. Although there is no conclusive evidence of aberrant psychological, physiological or anatomical structures or functions in PWS (Kehoe, 1998) stuttering has been cast as an impairment within a medical frame which seeks to trace etiology, pathology and manifestation. As such it has inherited the same status as any other disease, disorder or impairment such as asthma, visual impairment or spinal cord injury.

This methodology of biomedical practice (Mishler, 1989) applied to stuttering practice, requires that a disorder is accounted for by *deviations from the norm of measurable* variables. Deviations of fluency are considered in “assessing and measuring” stuttering. Within a normalising tradition of practice, it aims to establish “difference” from what is constructed as “normal” and transforms this difference into “deviance”. Differences in fluency are interpreted as *deviance* and constitute the “disorder” of stuttering. The clinician, in the role of a *neutral, idealised scientist*, “objectively” measures the stutter. Stuttering (as a “disease” entity) is placed under a microscope as the specific details of the disfluency are expanded “objectively” so that they can be understood in greater detail. As a result the context, which is so central to understanding stuttering, is deleted. In other words, by focusing on the norm deviation, the disorder has become MAGNIFIED. What has not been subject to a similar expansion is the person and context through which the disorder can be understood. Bio-medical modeling rests upon the doctrine of ‘*specific etiology*’ which seeks to confirm that there is a specific causal entity generating any disorder. This is based on the assumption that disorders have specific features that are universal regardless of history and culture (Gergen, 1994a; Turner, 1999).

As a consequence of such practices, a putative gulf has been established between 'patient' and 'doctor', with a significant power advantage lying within the expert, the penetrating gaze of the professional (Hunter, 1991). The result of this power imbalance for the now pathologised patient is his role as a passive recipient of medical expertise. His subjective lifeworld interpretations of disease are largely discounted by the clinician. What is important to add to these points, however, is that professional discourse acquires power and legitimacy through the process of social awareness. This process begins within commonplace cultural traditions such as people becoming 'aware' of patterns of difference. There is concern that the person has difficulty speaking, hearing, thinking in their lifeworlds. However, when such concerns are interpreted technically, the lifeworld experience and their concerns receive little emphasis, and the disorder becomes primary. The expert professional knowledge is privileged and valued (Gergen, 1994a). The eye of the clinician becomes autonomous from the patient's experience and sense of disability (Sullivan, 1986 in Henderson, 1994), a one-sided "outsider" view. An analogy offered by Leder (1992) is that of fashion, where the living body is used as the carrier of externally applied normative values which results in personal identity being stripped away.

In professional terms, a sense of personal identity is purported to be provided by the "case history", an essential and preliminary part of the clinical encounter. Yet as Sacks (1985) has pointed out, a clinical case history in reality explains little about the individual and his history. It traces the history of the disorder, not the person and his struggles with the disease. At its most arid, a case history, as the primary method of understanding the individual, lacks a metric for understanding the inner hurt, despair and moral pain of those who live with disorders (Greenhalgh, 1999). Furthermore, a biological orientation to stuttering simultaneously masks the social creation of disorders, minimising the significant influence of familial, occupational and sociocultural forces (Gergen, 1994a).

One might argue that clients and clinicians talk. I agree but feel that the talk is often around a technologically-generated script, about the stutter, the disorder. There are two, competing, stories about the disorder that are created in the clinical context (Hunter, 1991). The first is the patient's story of experience. That same story is likely to be reinterpreted by the practitioner as a transformed, medicalised, depersonalised narrative and presented to the patient in an alien form. Although sharing similarities, both stories are constructed from different points of view and with different motivations and themes. The argument here is that given the power of scientific

medical practice, the patient is socialised into believing that his story is not as important as that of the clinician (Gordon, 2000, Hunter, 1991).

The consequences of the medical influence in clinical practice is evident in the emphasis on symptomatic dimensions of fluency management prevailing in the literature. For example, in a comprehensive survey of treatment methodologies and treatment outcomes (Blood, 1993; Cordes & Ingham, 1998; Snyder, 2000), the prominence of fluency and symptomatic management is evident. Cordes & Ingham (1998), for example, selected only those programmes which had one or more of the treatment elements promoting changes in speech fluency as legitimate. Examples of treatment elements include: controlled breathing patterns; easy onsets to sounds words or phrases; altered vocalisation; gentle or modified articulatory gesture. This reveals their bias in favour of targeting motor-speech changes in therapy. In contrast, the considerations of life experiences or issues of self and identity do not feature prominently.

Snyder (2000) argues that almost any technique can reduce stuttering or disfluency in the short-term. Basing his argument on empirical evidence, he is emphatic that treatment approaches promoting only fluency modification have poor long-term treatment outcomes and that therapies create unnatural, embarrassing and unfeasible post-therapeutic speech. Therefore, he agrees that treating the symptom alone is not effective. Sheehan (1984) and Quesal (1998) add their voices to the debate by suggesting that while improved fluency is a desired treatment outcome, the ideal of “normally fluent” is not always achievable. Quesal (1989) asserts that fluency changes should not be the only aspect considered in determining treatment outcome, and has actively promoted the expansion of outcomes statements to include quality of life issues. I want to emphasise that issues of fluency are important in the lives of PWS. However, in my view even the management of fluency cannot be reduced to a technical exercise and divorced from people and their lifeworlds.

As a means of strengthening my argument I offer commentary on a sample version of a typical clinical report (Appendix A) and treatment plan (Appendix B) presented in a popular clinical manual by Hegde (1998). These documents and supporting commentary illuminate the points I have made about the medical bias in clinical practice with stuttering.

It is also significant that clinicians surveyed in a variety of contexts internationally have revealed their dilemmas and dissatisfaction in the way they manage stuttering (Baker, Ross & Girson, 1997; Cooper & Cooper, 1996; Starkweather, 2001). In a South African study, for example, Baker, Ross & Girson (1997) reported that 88% of clinicians were uncomfortable with treating stuttering compared with other speech disorders, given that stuttering is not easily cast as a medical, correctable, curable phenomenon. A large percentage of respondents (60%) felt they had inadequate skills to manage the most fundamental problem of PWS, that of emotions. Starkweather (2001) argues that negative emotions are the most important part of the stuttering problem and clinicians have little or no theoretical training about emotional dimensions. He suggests that it is not unusual that clinicians have such feelings of inadequacy in managing stuttering because they are unable to deal with issues that really matter for those who stutter.

My concern is that while it has been recognised that subjective dimensions of the stuttering experience are important, there has been limited questioning of the more fundamental concerns about the foundations on which our clinical practices have been based. I agree with Starkweather (2001) that there should be an improved educational curriculum for clinicians working with PWS but I argue that a more fundamental and prerequisite shift must occur which problematises our traditional constructions of stuttering and PWS in a medical frame. In Snyder's (2000) review of treatment programmes and outcomes, symptomatic, acontextual, "objective" treatment regime pretending to cure, is failing. It is also of grave concern that speech pathologists, as a group, internationally, have the most negative attitudes and stereotypical views of PWS which are also resistant to change (Snyder, 2001). It is not surprising because clinicians, through their training, have been socialised into a narrow, medicalised, deficit understanding of PWS. Within a medical frame, professionals seek to normalise or "control" stuttering. The professional's work is embedded within a broader social frame promoting normalisation (Corker, 1999) which assumes that the values, norms and behaviour of "mainstream" society or dominant groups in society are desirable. As a consequence, the professional retains authority, and promotes fluency methodologies, perhaps uncritically.

The recent survey of 71 members of the National Stuttering Association in America, participants about their treatment experiences (Yaruss, Quesal, Reeves, Molt, Kluetz, Caruso, McClure & Lewis, 2002). Although their responses to treatment varied, there was a concern that their social experiences have been neglected by clinicians. They

also recommended improved training for Speech-Language Pathologists. In another a large-scale survey (Hayhow, Cray, Enderby, 2002) of adults who stutter in Britain, it also became evident that there was a need to integrate treatment approaches with lifeworld experiences. Participants suggested that there should be more emphasis on daily coping strategies in addition to fluency skills. Further to this the anecdotal evidence in the numerous stories written by PWS have different responses to effectiveness of therapy. However, they retain a core suggestion that PWS should be understood as people, and that their concerns about stuttering are grounded in their everyday lives (St. Louis, 2001).

1.2.2 New imperatives for practice

The medical model has been challenged by many (Frank, 1995; 2001, Gergen, 1994a; Sacks,1985; Turner, 1995) and has received mounting criticism in medical literature particularly in the past two decades. It has been challenged as the social orientation to health and disability has presented a counter theory by reframing core constructions of disorder and disabilities. The contrasting positions of the medical and social models are summarized in Table 1.

Table 1: Contrasting positions of Medical and Social models to Disability

Medical	Social
Personal tragedy theory	Social oppression theory
Personal problem	Social problem
Individual treatment	Social action
Medicalisation emphasis	Self-help emphasis
Professional dominance	Individual and collective responsibility
Expertise orientation	Experience orientation
Care-centred	Rights-based
Control interest	Choice interest
Policy	Politics
Individual adjustment	Social change

Source: summarized from Oliver, 1996

The social model of disability, inspired by disability activists internationally (Oliver, 1996; Barnes, Mercer & Shakespeare, 1999) presents a challenge to the bio-medical model by raising issues of social discrimination, isolation, exclusion and dependency

on professions and professional intervention. It has sought to recast the disorder/disability debate within a sociopolitical experiential framework:

The social model focuses on the experience of disability, but not as something which exists purely at the level of individual psychology, or even interpersonal relations. Instead, it considers a wide range of social and material factors and conditions such as family circumstances, income and financial support education...At the same time, the individual and collective conditions of disabled people are not fixed, and the experience of disability therefore also demonstrates an emergent and temporal nature. This spans the individual's experience of disability, in the context of their biography, social relationships and life history.... (Barnes, Mercer & Shakespeare, 1999:31)

Barnes, Mercer & Shakespeare (1999) emphasise that anyone seeking to understand a person with any form of disability must rely upon the individual's experience of disability, their situated biographies, their social relations, and the wider social circumstances - in short, their life history, thus creating impetus for this study. In essence the social model has developed from a recognition and appreciation of experiential validity (Corker, 1998).

The social model juxtaposed with the medical model has provided a creative tension and a discursive space for rethinking ways of working in the medical and related disciplines. While the medical and social models have contrasting emphases, they share a common concern for human suffering and some would argue that it is impossible to work strictly within a medical or social frame (Hunter, 1991; Greenhalgh, 1999). Each approach considers the human condition through a different lens using different methodologies. Despite their differing orientations it would seem that need for engagement and perhaps reconciliation is critical because together they serve in the best interests of the person who lives with disorders in society (Bury, 2001; Conrad, 1997; Turner, 1997) The field of medical sociology in particular has been active in pursuing this engagement within the realm of personal experience research. I expand this point in the literature review that follows in Chapter Two.

Many professions, including Speech-Language Pathology, have begun to interact with the dialectic between the medical and social models for practice. As a concrete

response to this concern, the World Health Organisation (1999), has proposed the second version of International Classifications for Impairments, Disabilities and Handicaps, the ICDH-2, as a guiding framework for clinicians, with the express purpose of highlighting the social aspects of disability. The framework signals a shift away from the etiology of disorders and diagnosis, to the consequences of disorders (Thuriaux, 1995). The reconstruction of the tentative working frame is intended to guide clinicians by providing a broader and more meaningful characterisation of the health status of people in context. Whilst no policy guarantees a change in thinking, it does articulate the need to shift perspective from a completely medical way of working. However, the ICDH-2 continues to receive extensive critique from disability activists because it has retained a medical frame by placing impairment as central (Barnes, Mercer, & Shakespeare, 1999).

With reference to stuttering, Snyder, 2000, an advocate for PWS has called for a redefinition of the problem of stuttering. Aligned with the social model, he suggests a shift from describing stuttering as “broken words” to a social understanding of the phenomenon. He emphasises that only when such a shift occurs, will the speech-language pathologist’s role be redefined to include advocacy for PWS. This may counteract the negative social stereotyping of PWS, affording them the skills to manage issues of prejudice and discrimination that currently rob an individual of life choices while simultaneously creating disability. Internationally, PWS have become active in various forums. Self-help groups have flourished, conferences are held, and they seek to promote public understanding of stuttering experiences by varied means, including stories. They collectively challenge both the narrow construction of stuttering as a speech disorder.

Layered upon the social model of disability is legislation that actively favours a social construction of disability in many countries. South Africa is a good example. As a result of its sociopolitical transformation in 1994, the Department of Health has legislated various policies: National Health Policy of the African National Congress; the White Paper on Integrated National Disability Strategy (1997); National Rehabilitation Policy and Primary Health Care (PHC) service delivery framework to promote social concerns. Amongst the many dimensions of PHC, for example, is the necessity to develop relevant health care in a collaborative way with PWD, and with communities in general. This orientation presents a challenge for clinicians steeped in a medical tradition to shift emphasis from disorder/impairment to the person and social consequences of impairment. At a practical level the need for collaboration

with the people we work with is articulated by the Batho Pele¹ philosophy which puts the client first and envisions him as an integral part of the health care team.

Parallel to international trends, disabled people in South Africa have also taken on a minority group status especially in the post-apartheid era. This is evident in the numerous organisations promoting the rights of disabled people e.g. Deaf Association of South Africa (DEAFSA), Disabled People of South Africa (DPSA). PWS have promoted their interests through organisations in different regions in South Africa e.g. via Speakeasy Associations. Given the inherent diversity among PWD in South Africa, it has also been observed that (Rule, 2000, personal Communication) those with communicative impairments appear least powerful. She explains that this is due to the nature of their impairment which does not afford them the advantage of making their concerns heard (Rule, 2000, personal communication). While issues of equity, justice and democracy are firmly on the reconstruction agenda in South Africa, it is possible that people with disorders of communication have the potential to remain oppressed. Within such a changing reality, speech-language pathologists must remain vigilant about the social, cultural, political dimensions of practice as a means of being socially accountable. In my practice context it has become increasingly important to understand lifeworld realities especially as the diversity of life circumstances of PWS becomes increasingly visible, as traditional apartheid boundaries are dismantling. The need for research is paramount amid such changing realities.

In the discussion thus far I have made a case for the importance of understanding life experiences of PWS in clinical practice and explored why this has received marginal coverage in the dominant clinical enterprise. In the light of new policy and social and contextual imperatives, it becomes increasingly important for clinicians to critically reflect on their practices. In my view, such changes, which seek to admit life experiences in the clinical arena, promote the need for an expanding theoretical base through relevant empirical study. Theorising life experiences of PWS can be one of the many avenues contributing to such a theoretical base.

¹ Batho Pele: Batho Pele is the name given to the South African Government initiative to improve the delivery of Public Services. In Sesotho Batho Pele means "People First". The name was chosen to emphasise that service delivery should be people-orientated. The principles and values governing the public administration initiative are formalised in the Constitution (1996) and all constituencies are obliged to practise within this framework. The emphases include consultation with citizens to afford accessible and quality services in an atmosphere of openness and transparency.

1.2.3 Knowledge Productions Concerns

I continue to develop my rationale for this study by shifting focus to a critical examination of the research domain in stuttering. Here I question why the theorising of life experiences has received minimal emphasis in stuttering research. I approach the discussion by critiquing the dominant paradigmatic underpinnings of the research methodology, providing a review of the thematic emphasis in stuttering research, and presenting detailed critique of the little available research on experience and stuttering. In this part of the review I illuminate the contributions, gaps and silences as a means of strengthening the rationale for this study. I review the thematic and methodological thrusts in stuttering research as a means of demonstrating why life experiences and issues of identity have received minimal emphasis in the available literature.

There are two primary issues, which, in combination, reveal the concerns I have about the knowledge produced. Firstly, in concert with the medical model, pathology has become the metaphor guiding the construction of knowledge in a discourse which speaks of deficiency and deviance. There is an interest in the nature and causes of stuttering i.e. disorder dimensions. By comparison there is less emphasis on stuttering in the social world, about PWS, and an almost blanket silence on positive dimensions of PWS. Secondly, as a consequence of producing knowledge shaped by the combined effects of the medical model and a positivist paradigmatic hegemony, the emphasis on subjectivity and life experiences has received minimal coverage.

How have we researched?

In my analysis the published English-language research in stuttering between 1940-2003, is by and large, premised on the tenets of the positivist paradigm modeled on natural science ideology. It is driven by a technical interest that strives to generate causal or instrumental knowledge. Within this orientation it is assumed that reality can be revealed, is unitary, and that it can be understood via the application of the scientific method (Connoles, 1993). Knowledge construction in this paradigm is, therefore, aimed at producing an accurate imprint of reality, of stuttering. The researcher and researched exist as separate entities, with the researcher construed as neutral and at a distance. Precautions are taken to reduce the influence of the investigator and object on each other and data is intended as acontextual, with

replicable findings admitted as “fact”. The claims of truth and reality are supported by experimental and manipulative methods that generate knowledge of a technical nature. Data is most often quantified and managed via reductionistic processes, commonly aided by the use of statistics (Perkins, 1997).

The professions’ notion of the science has been largely influenced by its cultural alliance with medicine as well as other disciplines such as Psychology and Linguistics, which have historically adopted the scientific method (Pillay, 2003). The scientific method in turn has been uncritically and hegemonically promoted as “science” and as the prevailing way to produce knowledge. The early theorists and researchers in stuttering in the 1940s, namely Van Riper and Sheehan, were critical of the application of the dominant science and emphasised the importance of using methodologies suited to human studies in stuttering research (Van Riper, 1973). However, their voices were lost as the hegemonic political thrust of the dominant science prevailed for over five decades. Within this reality researchers in the field of stuttering adopted (uncritically) a positivist stance and have used this version of science with slight modification for five decades (Perkins, 1996; 1997; 2000).

In the latter part of 20th century several disciplines including medicine, anthropology, psychology and education questioned and began renewing their notions of science (Denzin & Lincoln, 1998). Their shift has been in the direction of methodologies more suitable to the study of human beings. Speech-Language Pathology is also shifting its thinking, but more slowly than other disciplines like Medicine and Psychology (Pillay, 2001b). Pillay (2003) argues that although there have been shifts in method in the profession, the epistemological and ontological underpinnings of positivism remain (Pillay, 2003). In stuttering research methodological shifts are also taking place, but in my assessment it has been lethargic. Only as recently as 2001, there was an appeal to give serious consideration to qualitative methodologies (Tetnowski & Damico, 2001). Let me concretise my claims.

Within a positivist tradition, the experimental design has become synonymous with “scientific” research in stuttering. The exceptional reliance on the experimental and quasi-experimental method is clear in the majority of the 600 studies reviewed by Bloodstein (1995) spanning fifty years (1944-1994), and in the data base held by Kuster, University of Minnesota, of published English-language research in stuttering between 1987 and 2002 in Speech-Language Pathology journals (<http://www.mankato.msus.edu/dept/comdis/kuster/Bibliography/Bibliography.html>).

Although dominant, experimental designs do not constitute the sole methodological tool to research the phenomenon of stuttering. Descriptive survey, quasi-experimental research, and a scattering of single-subject designs and longitudinal (Mowrer, 1998) have also been used. The reliance on quantitative analysis techniques has remained popular in most research despite the inherent difficulty in quantifying the complexities of stuttering (Perkins, 1996, 2000, Tetnowski & Damico, 2001).

Experimental designs have been used to compare stutterers and nonstutterers in terms of speech rates, patterns of disfluency, frequency of disfluency, reaction times, auditory processing skills, attitudinal scales, self-perception tasks, cognitive tasks and social skills (Bloostein, 1995). The intention has been to isolate differences between stutterers and non-stutterers as a means of speculating the causes or the nature of stuttering. In other words, the vast majority of studies using experimental designs have as their aim the generation of certainties or 'facts' about stuttering for the purpose of generalising findings. The singular, uncritical and weighty reliance on this method in stuttering research has not served the profession well (Freeman, 1999, Lebrun, 1998, Perkins, 1996, Quesal, 1998). Silverman (2001) argues that research studies in America have been contaminated by a single flawed assumption that stuttering behaviour can be researched independently of individuals.

As a consequence of this assumption, the heterogeneity among PWS has not been given careful consideration in research. As a consequence, the divide has been between stutterers and non-stutterers with little consideration of the differences which may exist within a group (Quesal, 1999). Freeman (1999) warns that unless we consider this basic issue we will fail to understand stuttering because we will be working from the assumption that stuttering is the same in all instances i.e. within the group of stutterers. The central critique of significance to this study is that the data generated through the application of the experimental design may assist in understanding group phenomena but it has limited application in understanding the individual case. Quesal (1999) adds his voice to this argument by highlighting the considerable diversity among people who stutter. Among the common over-generalisations occurring as a consequence of uncritical applications of experimental research, is that stuttering is a genetic disorder, stutterers have faulty motor systems, and that there is only one cause of stuttering. The impact of these over-generalisations is most seriously experienced in clinical practice through treating all PWS alike, for example by assuming that stutterers have faulty motor systems.

A further feature of experimental designs of relevance here is individual context stripping. In experimental research the aim is to control the context so that the extraneous variables or contextual factors may be reduced (Tetnowski & Damico, 2001). By so doing, the dynamism and complexity of the context, specifically the context of the individual, is lost. Stuttering resists understanding outside of context. Furthermore, because human beings and communication are essentially diverse and dynamic, it is virtually impossible to achieve matched and controlled groups leading to difficulty in replicating the findings in experimental designs (Tetnowski & Damico, 2001). There are two key consequences of this. Firstly, that the knowledge generated in these highly controlled contexts offer little application to the real world. Secondly, and by virtue of the inherent difficulties in matching the experimental and control groups across various laboratory sites, the “facts” generated by the research are contestable but are they are often uncritically accepted as “true”.

Positivist research wisdom dictates that the verification or falsification of hypotheses is independent of theoretical and observational languages. The requirement for an inquiry to be objective is that hypotheses must be configured independently from the way in which facts are collected. The researcher's theoretical influence in conceptualising the study, his penetrative gaze, the selection of what data is produced, the development of the instruments, and the pretended non-admittance of subjective aspects of analysis, are all issues of core concern. Put another way, I would argue that the “facts” about stuttering are not “out there” realities but essentially human constructions that are contestable. In other words, people (researchers) have created the idea that stuttering is linked to central auditory processing problems or motor-skill deficits. It is not that stuttering is so. However, in presenting research as value-free or value-neutral, untainted by human intervention, the research consumer is likely to accept “fact” as truth. The research is not innocent. It has been guided by the medical model (within a positivist epistemology) and therefore the search for biological differences is prominent.

Having problematised the issue of facts being “out there”, it also becomes important to consider where the knowledge has been produced. The majority of stuttering research has been conducted with white, middle-class, male, American and British English-speaking subjects, and by researchers who are predominantly white, male, American and British professionals: a male-stream knowledge. Given this arrangement, a glaring concern regarding the “facts” is that they are interpreted as generalisable and universal in nature but may have limited application to anyone

outside of their normative research criteria. It is unsurprising that those who are not White, middle-class and male are considered “atypical”. Anyone who is old, female, black, mentally retarded, or of “Other” cultural and linguistic backgrounds has been regarded (problematically I might add), as an “atypical stutterer” (St. Louis, 1986). There has even been a struggle to admit female subjects and gender issues into the research domain (Silverman, 2001). In my context in South Africa in which diversity is becoming a celebrated reality, I have often found the application of such research problematic because of the limited application for the individual who has a fundamentally different lifecourse and biographical profile to the “typical stutterer”.

A further consequence of “objective” orientation is that the interest in the generation of “facts” cannot accommodate issues of human purpose and agency. As the researcher is cast as “objective outsider”, he cannot engage with the purpose the meanings people attach to particular behaviour and is in danger of discounting the very human (and subjective) side of understanding communication and communication disorders. The objective outsider’s view runs serious risk of having little bearing on the “insider’s” view. Outside of agency concerns, Perkins (1997, 2000) has cautioned that we will fail to understand the very nature of stuttering by reliance on the objective perspective.

Stuttering has two heads facing Janus-like in opposite directions. They are so dissimilar that the evidence for one seems so unconnected to the other. Yet both are integral parts of the same problem. One head faces outward. It is the observer’s view of stuttering; the behaviour that can be heard and seen and has been the basis for scientific definition of stuttering since the beginning of most systematic research almost three-quarters of a century ago. The listener-dominated definition of stuttering has prevailed. The other faces inward. It is the private experience of the involuntary core - the sudden inability to make the tongue, lips or jaw move to the next intended sound... (Perkins, 2000:17).

Perkins (1997) explains that as a consequence of the reliance on objectivity, researchers have shifted the definition of stuttering from a speaker definition to a listener definition. This, in turn, has generated a host of other concerns (which I do not attend to here) because there is no listener agreement on stuttering. Furthermore, given the importance of objectivity, the very terminology has changed from stammer to stutter in America. “Stutter” is intended to foreground the overt,

observable condition whilst “stammer” had typically been associated with subjective dimensions (Perkins, 2000).

As a consequence of the vast knowledge base generated by quantitative, experimental methodologies, there has also been a simultaneous exclusion of psychosocial concerns. The problem is not a new one. More than a decade ago, Quesal (1989) challenged the profession for a lack of engagement with the core psychosocial concerns of PWS in an aptly titled article “Have we forgotten the stutterer?” He has argued cogently that as a consequence of difficulties in quantifying psychosocial factors these issues were being interpreted as a lack of reality, that is, if we can’t count or measure it, it does not exist. Research in this domain has, to date, been minimal.

Silverman (2001:4) provides a succinct critique of how the research outcomes within a positivist frame have (not) served clinical practice:

The fact remains that people seeking help with stuttering problems are just that - people. And the information that therapists have from those conducting research and writing books i.e. the means, standard deviations etc. simply don’t address that fact very well. The Method of Science with all its assumptions about reality from a human perspective including the need for objectivity of the so-called observer, linearity of experience and the uses of inferential and descriptive statistical analyses to interpret observations simply can not, at this point in space-time, generate information completely useful to modify behaviours of multitasking, complexly functioning human beings. Personal, more than impersonal, knowledge is required to inaugurate, modify and stabilise and maintain behaviour change.

In summary, what I hope to have demonstrated in this brief review is that the research “truths” accumulated about stuttering over the past thirty years have created a collection of deficit-centred and totalising “facts” about stuttering. In addition, stuttering has become naturalised as a fluency disorder and has given rise to prescriptive assessment and practice. My central argument is, therefore, as I have highlighted in the Preface of this study, that this position is fundamentally at odds with my experience of people who stutter.

Weighty thematic emphases on Disorder

In this part of the discussion I shift emphasis away from the research methodology to the thematic interest of research studies. Here I demonstrate that research has been directed largely at understanding the stutter, the disorder, with marginal interests in the person who stutters or the social contexts. This review is based on my analysis of a comprehensive database of stuttering research over the 1987-2001 period compiled as part of an ongoing project at the University of Minnesota website (<http://www.mankato.msus.edu/dept/comdis/kuster/Bibliography/Bibliography.html>) with selected exclusions². In Figure 1, I represent the spread of research thrusts and thereafter comment briefly on the emphasis within each strand. My intention is not to provide an exhaustive review of stuttering literature but rather to demonstrate the weighty emphasis on producing knowledge about stuttering, the disorder. Where relevant I expand on some issues.

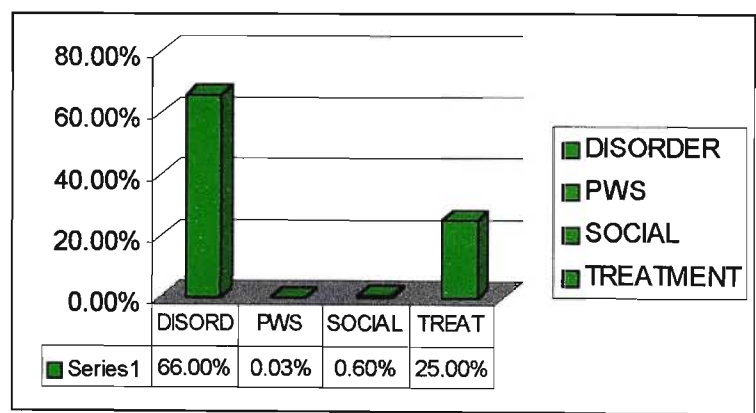


Figure 1: Thematic emphasis in stuttering research

The bulk of research (66%) has been around the nature and causes of stuttering i.e. an emphasis on disorder. Given the multidimensional nature of stuttering, there has been a wide range of studies exploring different dimensions of the disorder particularly physiological dimensions. Among the many studies I cite a few examples

² Exclusions: I have excluded the articles pertaining to research methodology, commentaries, book reviews and cluttering.

merely to provide a cursory glance at the nature of thematic interests. These studies are on

- ◆ lateral dominance (Blood & Blood, 1989; De Nil, Houle, Kapur & Kroll, 2000);
- ◆ motor-speech skills (Boutsen, 1995; Boutsen, Brutten & Watts, 2002; Cross & Olson, 1987; Denny & Smith, 1992; Guitar, Guitar, Neilson, O' Dwyer & Andrews 1988; Kelly, Smith & Goffman, 1995; Shultz, 1991);
- ◆ sensory and perceptual processes (Amir & Yairi, 2002; Barasch, Guitar, McCauley & Absher, 2000; Bosshardt, 2002; Kalinowski, Stuart & Armson 1996);
- ◆ genetics (Drayna, 1997; Hall, Amir & Yairi, 1999; Pellowski & Conture, 2002; 1997);
- ◆ speaking rate and symptomatic presentations (Bosshardt, 1990; Colcord & Gregory, 1987; Cordes, 2000; Kalveram, 2001; Logan, 2001; Ryan, 2001;
- ◆ Parent's speaking rates and stuttering (Guitar & Marchinkoski, 2001; Guitar, Schaefer, Donahue-Kilburg & Bond, 1992; Kelly, 1993; Langlois, Hanrahan & Inouye, 1986; Zebrowski, 1993);
- ◆ developmental trends including speech-language development (Arndt & Healey, 2001; Bloodstein, 2001; Caruso, Ritt, & Sommers, 2002; Conture & Melnik, 2000; Kloth, Jansen, Kraaimat & Brutten, 1998; Lindsay, 1989; Miles & Ratner, 2001).

These studies have been directed at understanding the nature and causes of stuttering. I do not think that they are unimportant. However, in the context of this study my concern lies with the exclusion of life realities and the limited application of such knowledge in the clinical context.

The research relating to PWS has been interested in their personalities, their performance at school and in the workplace, their attitudes towards communication, and the efficacy of 'self-help' groups. Studies on personality have compared

personality of stutterers with nonstutterers on aspects of adjustment to the disorder, psychosexual fixation, self-perceptions and expressive behaviour, and anxiety by using a variety of variable-centred measures of psychological origin. The findings remain inconclusive and inconsistent for the group of PWS as a whole (Bloodstein, 1995). However, the accumulated evidence does not suggest that the average or typical stutterer (whoever that may be) is distinctly neurotic or severely maladjusted, or that there are any specific kind of broad-set personality traits that are typical of stutterers as a group. Also, there is recognition that there is extreme overlapping between stutterers and nonstutterers with respect to adjustment, suggesting that some stutterers have healthy emotional dispositions.

There are also those stutterers who have poor self-esteem and demonstrate social anxiety (Kraaimat, Vanryckeghem & Van Dam-Baggen, 2002), which may contribute to maladjustment and insecurity (Bloodstein, 1995). The attitudes and of PWS towards communication have been investigated and debated, and continue to be a source of interest for researchers (Blood, Blood, Tellis & Gabel, 2001; Vanryckeghem, 1995; Vanryckhem & Brutten, 1996; Vanryckehem, Hylebos, Brutten & Peleman, 2001; Watson, 1987). While the group results indicate that stutterers have negative attitudes towards communication, the results of individuals demonstrate that this does not hold for all stutterers.

The interest in generating knowledge about issues of self-concept and self-esteem is relevant to the clinical context, but has been investigated within a positivist frame. Green (1999), for example, explored the relationships between self-conception to the perceived severity in stuttering in adults and children using a variable-orientated methodology. His findings suggested that the more severe adults perceived their stutter to be, the poorer their self-conceptions. The results for children, however, showed an inverse relation (compared with adults). Green suggests that the varying results may be suggestive of different experience histories with stuttering. As a recommendation, therefore, he concurs with the suggestion by Brutten & Vanryckeghem (1993) that developmental models of stuttering should be based on differences in life experiences of PWS, and recommends the expansion of the methodological toolbox.

There is little available literature on the development of PWS in their lifeworlds and identities over time. Instead, the literature is directed at the interests of the development of stuttering (the disorder) over time from its initial appearance to its

advanced stages. Theorists and researchers (Bloodstein, 1960) have therefore presented stage and track (Van Riper, 1982) or level (Guitar, 1998) models for understanding the development of *stuttering* over time based on observations of behavioural dimensions. Peters and Starkweather (1989) made a contribution by exploring the development of stuttering into later adulthood. They considered the multidimensional changes in speech-motor, linguistic, social, emotional, linguistic and cognitive behaviour through five stages of development of the individual who stammers from preschool to maturity. They compared these changes to individuals who spoke fluently and suggested that the development of stuttering could only be explained by understanding the interconnected influences of social demands and physical maturity. Van Riper (1982: 92) makes the limits of such models clear:

We must confess that we have never been comfortable with criteria for our own developmental stages. Too many of our cases have resisted placement in any of them. The inadequacy of this sectioning and categorising now seems quite clear, and when adequate longitudinal data are available the concept of phases or stages will be completely discarded. Human beings have a ways of slipping through meshes of all categories. We are tired of wielding empty nets.

At a societal level, the research interest has centred round prevalence and incidence studies, examining stuttering in various cultural, social and work contexts, as well as stereotyping. While the importance of context has been considered, it has been included with intention to understand how such contexts might contribute to causing or maintaining stuttering, hence retaining an central emphasis on the disorder. Research studies have considered parent's styles of interaction and communication, traits, emotions and child-rearing practices (Adams, 1992; Ratner, 1993). For example, Meyers & Freeman (1985) found no differences between mothers of children of nonstutterers and stutterers. However, they reported that the speech rate of mothers was faster with stutterers. Other studies Langois, Hanrahan & Inouye (1986), Shulze (1991) and Kelly & Conture (1992) did not find any differences in speaking rate, turntaking and interruptions. It is apparent that these studies reveal conflicting findings. This is not unusual as Bloodstein (1995: 268) concluded "experimental analogues of life situations are not the real thing".

The research on stuttering in the school environment has been considered from different perspectives. These include the grade placement, educational achievement,

and educational adjustment of stutterers. In general, it has been found that stutterers do not perform as well as nonstutterers on academic aspects, with difficulty in speaking in class highlighted as one of the factors (Knudsen, 1939; Hugh-Jones Smith, 1999). Cox, Seider & Kidd (1984) in contrast found no difference in the educational adjustment of stutterers and nonstutterers. Hugh-Jones & Smith (1999) reported a common finding that the majority of PWS reported that the negative consequences of stuttering were most evident in the school context. Other studies coincided with findings that children who stutter report frequent episodes of teasing (Langevin, Bortnick, Hammer & Wiebe, 1998). They suggest that the psychological impact of teasing is devastating, and the effects carry over into adulthood.

While the emphasis on the local contexts of home, school and work (Silverman & Paynter, 1990) is critical, the results do not receive interpretation within the broader societal context as a means of providing a social perspective for interpretation. In the absence of problematising issues like gender, social values and expectations in such contexts, the individual case receives restricted interpretation. Knowledge becomes acontextual and ahistorical, running the risk of being interpreted as “universal” i.e. one could assume that all contexts are similar.

The understanding of stuttering across various countries and ethnic groups has been researched since it is acknowledged that people may have different beliefs about stuttering (Finn & Cordes, 1994; Shames, 1989). While a multicultural agenda is valuable given the inherent diversity across the globe, this research agenda seems to rely on a narrow conception of multiculturalism in the profession that is interested primarily in race and ethnicity dimensions (Pillay, 2001a). The research interest (in very few studies) has been about how blacks and whites or linguistic groupings differ or are similar in symptomatic presentations of stuttering (Aron, 1962; Robinson & Crowe, 1987; Van Borsel, Maes & Foulon, 2001). My concern is that this narrow, variable-centred orientation does not account for the complex and multidimensional notion of culture at play in the daily lives of women, men, children, poor, rich, black and white, American, Indian, gay and People Who Stutter (Kathard, 2002).

The research emphasis at a societal level has considered issues of stereotyping. The perceptions of varying groups of nonstutterers about their opinions of stuttering and PWS have been investigated. The negative stereotyping of PWS as quiet, reticent, introverted, passive, tense, anxious and afraid, is robust in the literature. These negative stereotypes are held by employers and vocational counsellors Craig &

Calver, 1991; Silverman & Paynter, 1990; teachers and special educators (Ruscello, Lass, Schmitt, & Pannbecker, 1994); parents (Fowlie & Cooper, 1978); professors (Silverman, 1990) and PWS (Lass, Dennis, Pannbacker, Schmitt, Middleton, & Schweppenheiser (1995). Of significance, and as already mentioned, is that speech pathologists, including students, as a group hold the most negative perceptions (Dietrich, Jensen, Williams, 2001; Leahy, 1994; Snyder, 2001,) even though the corpus of psychological data does not support the presence of distinctive or common negative personality traits (Snyder, 2001).

Ham (1990) suggests that the profession's definitions of stuttering are too narrow and that assumptions held about PWS, handicap the ways in which we approach treatment. While it has been established that the varying groups of people surveyed (as indicated in studies quoted above) in Western countries hold negative beliefs and stereotypes about PWS, little is known about other parts of the world. In a recent pilot study about public opinions of stuttering in Denmark, Bulgaria and South Africa, there were varied responses across contexts. In general, it appears that stuttering is perceived negatively and received a similar range negative evaluations as being mentally retarded or overweight (St. Louis, Yarus, Lubker, Pill, Diggs, 2001).

The research interests with respect to treatment cover a wide range of issues. Among them are the outcomes of different treatments, efficacy studies, service delivery models, treatments for varying age groups, relapse, generalisation of fluency skills and long-term maintenance (Craig, 1998; Craig & Hancock, 1995; Langevin & Boberg, 1996; Lincoln & Onslow, 1997; Mallard, 1998; Murphy & Quesal, 2002; Ramig & Wallace, 1987; Reardon & Reeves, 2002).

In summary, I re-emphasise that the research interest has been focused primarily on the nature and causes of stuttering. By comparison empirical studies on PWS and social contexts have received little coverage. This research thrust coupled with a positivist hegemony explains why theorising life experiences and identity formations has received minimal attention. However, I must add that although the range of themes have been widespread, we, as a profession lack an understanding of how the diverse range of issues – disorder, individual, culture, treatment, coping strategies and society coalesce in the context of a single life, changing over time.

1.2.4 Experience as data in stuttering research: Contributions, gaps and silences

I now examine the emerging issues, gaps and silences in stuttering research in published studies which have admitted the personal experiences of adults and have used narrative-based methods to produce data. I have selected English-language published studies in Speech Pathology with the exception of the unpublished doctoral study by Sue-O' Brien (1993) which makes a critical contribution to this review. My search did not reveal any study using life history methodology as I have proposed in this study. I must say again that innumerable life stories have been written by PWS. Given the importance of these stories in themselves (St. Louis, 2001), I raised the issue of why stories (in this instance autobiographies) were not admitted as a formal narrative *research* methodology with St. Louis during an the International Stuttering Awareness Day conference on-line conference, October, 2001). His response was:

I must confess I am more comfortable in the traditional research paradigm than in the realities of qualitative research. I began the project from a research perspective, trying to use qualitative methodologies to uncover some valid and reliable hints about the range of real experiences, negative to positive, which stand out in the minds of people. I am still carrying out lexical analyses, content analyses, and theme analysis but none of them seems to capture the richness of narratives like simply letting them speak for themselves. That is precisely why I wrote the book.

The point I make is that although many stories about living stuttering are available, they have not become a routine part of our research methodologies and the basis for theorising.

Petrunik and Shearing (1983), both PWS, investigated how stutterers cope with their disability. Their study, outside of Speech-Language Pathology, was published in a sociology journal. Motivated by their personal experiences of stuttering, they collected data between 1970 and 1983 in various clinical and field settings in Canada. They conducted interviews, reviewed clinical files and autobiographies and observed participants in various settings and examined the strategies used by PWS to manage interactional order and identity and reported that concealing, revealing and disavowing stuttering were primary coping strategies. Participants used a combination of premeditated and spontaneous strategies.

Theoretically, their discussion is informed by the work of Goffman (1963, 1967) and Schneider & Conrad (1980) on the management of stigma. Petrunik & Shearing (1983) extend this analysis by considering the importance of the experiential dimension in the construction of social order. They emphasise the links between behaviour, identity and subjective experiences as a means of understanding how stutterers manage interactional order. The subjective experience highlights that people may perceive their deviance as inner essence, which may be independent of behaviour i.e. it may not be observable. They concluded that stutterers were primarily concerned with preserving an acceptable identity and presence as a means of coping with everyday living. They make an important contribution in linking the interdependent issues of experience, identity and behaviour. Furthermore, they highlight issues of social concern by addressing how stutterers cope with stigma in society. However, while they consider adults who stutter, they do not offer a historical trace of experience. My concern is that the temporal dimensions therefore do not receive illumination. Furthermore, the biographical depth of participants and social contexts of experience are unexplored.

Sue-O' Brien (1993), with a counselling psychology background, explored the subjective experiences of eight participants using a phenomenological approach using a long interview method. Her intention was to rekindle an interest in the psychological dimensions of stuttering with a specific focus on the emotional aspects of stuttering that had long been neglected in stuttering research. Her study is embedded within the "Moment-of-Stuttering" theories designed to understand what occurs at the moment of stuttering in contrast to theories interested in causation and onset of stuttering. The study is concerned specifically with illuminating and understanding the "essential structure of stuttering" via a subjective lens. She makes a strong motivation for shifting from listener to speaker reconceptualisations of stuttering and presents an analysis of the unfolding experience of stuttering via a temporal lens.

Sue-O'Brien's (1993) findings are presented at two levels namely, the global (life experience) and incident level. At the global level she makes brief mention of vivid childhood experiences that appeared omnipresent and pervasive and became a governing influence through life. At the level of incident her analysis is detailed within a framework of before-during-after experience. She discusses stuttering as a temporal experience along four dimensions of anticipation, control, listener judgement and opportunities. The experiences unfold along a continuum e.g. control

- no control. Of vital importance is that the study outcomes have direct implications for the practice and training of graduates especially in the psychological-emotional domain.

While the study makes an important shift in admitting subjectivity, its emphasis is limited to phenomenological dimensions and therefore lacks critical purchase. The analysis is directed at personal (tragedy) dimensions and excludes an analysis of sociological concerns. Furthermore, while the data is gathered from individuals who stutter, she offers little biographical depth. In this regard the experience is acontextual. It does not reveal who the person behind the experience is, except for basic age and gender information.

Corcoran and Stewart (1998) with a Speech-Language Pathology background, accessed personal experiences of PWS using a long interview narrative methodology with eight adult participants between 25-50 years. Suffering emerged as a primary theme. The core experiences of stuttering were characterised by four key elements: viz. helplessness, shame, fear and avoidance. The results are discussed in relation to multiple theoretical bases from a various disciplinary backgrounds. Participants' helplessness are described in relation to a learned helpless hypothesis popularised in psychological literature. Shame is discussed in relation to Goffman's theory of stigma management offering a slight sociological perspective. Suffering is discussed in the context of the narrative methodological shift which affords the opportunity to understand a personal dimension of the experience, traditionally excluded in twentieth century medicine.

More recently, Crichton-Smith (2002) used in-depth interviews to explore the communicative experiences and coping strategies of 14 adults who stammer in United Kingdom. The participants, ranging in age from 26 to 86 years, had stuttered since childhood. They were of varied occupational backgrounds. The specific intention was to ascertain how adults manage stuttering in their day-to-day communication prior to, during and post-intervention. The interview was based on the five stages of development using the stage model proposed by Peters and Starkweather (1989). It covered specific areas as participants were invited to discuss their childhood, adolescence, employment, relationship and speech-language therapy.

Although similar types of experiences were available across participants, they perceived these differently. The common findings were that the experiences at school were unpleasant, and the major theme in childhood that of limitation, which continued into adulthood. They reported adapting to social situations by avoiding or minimising their stammer. They reported a fear of stammering as being instrumental in their difficulties. Participants managed their communication by using a variety of communication strategies that were explained as “no change”, “taught changes” and “intuitive change”. Six participants who reported “no change” managed stuttering by speaking without prior planning. “Intuitive changes” were those strategies which were purposefully instigated to manage communication. These included changing the tone of voice and doing something to relax. Many of the participants reported using speech techniques at particular times for example, after completing a therapy programme or when in a support group. They also reported knowing the “theory” of such techniques but did not mention using them as functional strategies.

There was also a lack of concern from some participants about maintaining fluency, suggesting that some had reconceptualised their need to be fluent. However, all participants viewed the elimination of disfluency as a desirable outcome. Many reported satisfaction with their speech therapy programmes with one participant stating that he abandoned the use of fluency techniques because it required too much effort. Highlighting or disclosures (telling someone you stutter) were often chosen strategies just before high-pressure situations, whereas in families and social contexts it was used after stuttering had occurred. The majority of participants reported using disclosure as a useful means of coping because it put the speaker and listener at ease.

The situational management of stammering was influenced by internal and external variables. These include the content and structure of the message, the status of the interlocutor, the familiarity of the communication partner, the formality of the situation physical and emotional states and past memories of stammering. Crichton-Smith (2002) concludes that the limiting experiences of stammering in childhood are carried through into adolescence and adulthood in areas of education, employment and self-esteem. Participants use multiple strategies to cope contributing to the limiting experience of stammering. Whilst the limiting experience of stuttering is explored, there is a no comment on the positive dimensions of experience and the exploration of social issues do not receive amplification.

While the studies reviewed make important shifts in method, they have not articulated an epistemological and ontological shift in their research orientation. By this I mean that their notions of reality have positivist inclinations. A singular notion of reality prevails and is evidenced as the PWS is situated primarily within a single, unitary, unchanging frame of reference, as one who stutters, within a deficit discourse. As a consequence, the "dark-side" of experience is emphasised. While I agree that it is important to hear and acknowledge the suffering which is central to the experience, and an aspect we have traditionally neglected, my concern is that the participant continues to be portrayed as passive and without agency.

The ideological underpinnings of the medical model dominate, retaining the individual as reduced and the experience as one of personal tragedy. There is a "macroblindness" to the social constructions of stuttering. Why do people act in the way they do? How has society shaped who they are and how they act? These aspects have been neglected. Furthermore, the participants and contexts remain without characterisation. I have raised this issue repeatedly and feel that it warrants further explanation. In the studies I have reviewed which use experience as data, the PWS receives no description beyond a basic biographical description. Who is this PWS? Are all PWS the same and why do they use similar or different strategies? Would this experience be the same regardless of race, gender, age, class, gender, education, occupation, and social realities?

In concluding, I hope I have made a case for theorising the life experiences of PWS in context by exploring the importance of life experiences from a therapeutic perspective. I have also discussed how the medical model coupled with a positivist science has resulted in a knowledge base that has made a minimal contribution to exploring and theorising lifeworld experiences and identity formations over time. Further impetus for this study derives from new policy and contextual realities in South Africa creating a need for theorising the life experience of stuttering where none exists. While the studies that have admitted first-person reports of PWS make a useful contribution to the knowledge base, they continue to be medicocentric. As a consequence the richness of the biographical and social emphasis is diluted and the participant takes on a singular "universal" position in the study as one who stutters. Furthermore, the problematisation of the experience within a social context has not occurred, and therefore these studies do not offer insight as to how contextual realities contribute to shaping experience.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL LANDSCAPE

In Chapter One I identified the gaps, silences and my concerns surrounding the *theoretical (thematic)* aspects of the research focus and argued that professional research in stuttering is interested in exploring various dimensions of disorder. As a consequence we have a limited knowledge base about lifeworld experiences of stuttering. Furthermore, I raised concerns about the dominance of positivist *research methodology* and the need to expand methodologies in the interests of diversifying and creating knowledge bases that serve clinical practice interests. My concerns are two-fold, namely *what (theoretical)* knowledge is produced and *how* (methodology) such knowledge is produced. This study, therefore, is intended to expand the professional knowledge base by attending to these *theoretical* (Chapter Two) and *methodological concerns* (Chapters Three and Four). I explore the identity formations of participants in relation to stuttering in lifeworlds over time (theoretical interest), using narrative life history methodology (methodological shift).

In this chapter I create the theoretical backdrop in two ways. The first part is a review of emerging issues from life experience research in medical and allied disciplines that have an active interest in personal experiences of disorder, illness and chronic disability. Although these studies are not specific to stuttering, they are relevant here because they have theorised the personal experience of illness and disability, and have adopted narrative-based methodologies. The research studies reviewed are of varied disciplines including nursing, medical sociology, psychology, speech pathology and occupational therapy. The primary theorists informing the discussion include Sacks (1985, 1990) neurology; Mishler, (1999) psychology; Frank (1995, 1997, 2001) sociology, Bury (1982,2001) and Williams (1999, 2001) medical sociology and Charmaz, (1987, 1995a, 1999) nursing. The second part of the theoretical backdrop is a review of research and theory on issues of self-identity formations over time, and social action drawing primarily on the work of narrative theorists viz. Lucuis-Hoene & Deppermann (2000), Mishler, (1999) and Somers, (1994), including other theorists and researchers where relevant. Although I have structured the discussion of theoretical (Chapter Two) and methodological components (Chapters Three and Four) separately for conceptual convenience, these are closely related. Therefore, it is unavoidable that they often come together

in the discussion because personal experience theory is commonly generated via narrative methodology.

At the outset I clarify the specific interests of this study because the literature selected and reviewed were guided by these interests. I am interested in the individual's experience of stuttering (through the lens of self-identity formation), in his lifeworld (personal/social), over time (temporal). *Personal experience* is a common/generic term used to describe the personal meaning people attach to aspects of their lives (Clandinin & Connelly, 2000). When people record such experience it is not recorded in raw sensory form or photographic form. These are narratives and need to be understood as such. *Stories are the "closest we can come to experience"* (Clandinin & Connelly, 1994), *hence the link between experience and narrative ways of knowing*. Here I am interested in the *personal meaning participants attach to stuttering in their lifeworlds over time, and the actions they take*. This notion of experience is different from traditional positivist/empiricist connotations of perception in two respects. Firstly, it is an active process of creative meaning-making in contrast to a single, fragmented notion of perception. It is not a passive reception of something outside the subject. Secondly, it is "global" and organic because it incorporates an overall subjective situation which is in turn connected with the whole life of an individual (Alvesson and Skoldberg, 2000). When people tell self-stories, or how "I" experience stuttering, they construct self-identities illuminating who they are and how they want to be understood. It is via these self-identities which form over time that they illuminate how they experience a particular phenomenon, and how and why they act in ways they do: "I act because I am".

In this study I have an interest in the *lifeworld* experiences of stuttering over time, that is of experiences in the everyday living contexts from childhood and adulthood. This is in contrast to the studies that may be directed at personal experiences of treatment in a clinical context. Although lifeworld experiences may include treatment experiences, it is not limited to this. In contrast to studies which have an interest in chronic disorders acquired in adulthood, this study is interested in experiences of stuttering as a *chronic* phenomenon persisting from childhood through adulthood. Furthermore, this study is interested in how *stuttering is negotiated* in the lifeworld i.e. social actions participants take in living with stuttering. In the literature, the terms like "coping", "adjusting", "managing" are frequently used. I use "negotiate" as a broad construct to include this diverse range of social actions in living with stuttering.

2.1 Life experience research in medical and allied disciplines

"The disease-the- man-the-world go together and cannot be considered separately as things-in-themselves" (Sacks, 1990: 229)

Sacks' statement impresses upon us the value of personal experience research because it brings together the experience, the person and the social world. Studies in chronic illness and disability, coping and lifeworld issues have been growing in popularity in the medical disciplines over two decades and have gained momentum in the 1990s (Thorne, Paterson, Acorn, Canam, Joachim & Jillings, 2002). Personal experiences of varying types of chronic illness and disability conditions across medical disciplines have been researched. From the published English language database in medical and allied disciplines I have reviewed a sample of literature to gain insights into emerging issues. The following are examples of focus on personal experience:

- ◆ traumatic brain injury (Nochi, 2000);
- ◆ cancer (Good, Munakata, Kobayashi, Mattingly & Good, 1994; Lee, 2001; Mathieson & Stam, 1995; Mathews, Lanin & Mitchell, 1994);
- ◆ hearing impairment (Perry, 1996; Kent, Furlonger & Goodrick, 2001);
- ◆ acquired language disorders (Parr, Byng, Gilpin & Ireland, 1997);
- ◆ epilepsy (Good & Good, 1994; Reis, 2001);
- ◆ asthma (Adams, Pill & Jones, 1997; Drummond, 2000);
- ◆ multiple sclerosis (Robinson, 1990);
- ◆ temporomandibular joint problems (Garro, 1994);
- ◆ colitis (Kelly & Dickenson, 1997);
- ◆ spinal cord injury (Yoshida, 1993);
- ◆ stuttering (Corcoran & Stewart, 1998; Sue-O'Brien, 1993)
- ◆ mental health (Busfield, 2000; Lysaker & Lysaker, 2002)

Personal experience research has become popular in the medical discipline for many reasons. Primary among them is that it actively promotes the "*peopling*" of the research process through valuing subjective experiences. Narrative methodologies especially have gained legitimate status. The insertion of the "Self" into the research process is not new because the early work by Mead (1934) and Blumer (1969) identified the centrality of the Self as a medium through which people interpret

situations and choose to act. Given the rise of positivism, researching the Self was not actively advanced. However, its importance was never doubted across many disciplines. Within the ambit of chronic illness and disability, early studies (Goffman, 1963; Strauss 1959) foregrounded the active role of individuals with chronic disability in making sense of themselves and taking social action. In the 1990s there has been a renewal of interest in the Self with all its complexity. It has become a useful conduit through which experience is mediated and understood (Bury, 2001; Charmaz, 1983, 1987, 1999; Conrad, 1987; Hyden, 1997; Morse, 1997; Williams, 1999; Yoshida, 1993), especially in the context of creative ideological tensions between medical and social orientations to understanding issues of impairment and disability. Personal experience research has become a fertile ground for examining the interplays between the medical and social dimensions of living with chronic conditions. In understanding how an individual lives with a condition, there is potential to engage with medical/impairment dimensions as well as social issues.

Personal experience research has also been popularised because there has been an *international rise of chronic disabling conditions*. In such contexts, management and care dimensions have superseded the medical treatment and cure (Gerhardt, 1989). The “medical intervention” has expanded to the “rehabilitation” of those living with chronic conditions, as the prevalence of conditions such as head injury, stroke and AIDS has increased in visibility (Hyden, 1997). Clinical practitioners, particularly in “rehabilitation” professions such as Physiotherapy, Occupational Therapy, Speech Pathology and Psychology, are faced with the enormously complex task of rendering appropriate services to people with chronic illness, creating a need to theorise life experiences, especially if they intend to aspire to excellence in their practices (Bury, 2001). In this vein, personal experience research makes an important contribution by illuminating the multifarious ways in which disabling symptoms interact with life worlds, that is, local living contexts (Bury, 2001), drawing to the fore the issues and concerns people with chronic disability face in a social terrain. The interest in lifeworld experiences has been promoted actively by disability theorists who maintain that chronic illness can only be understood if the social barriers and oppressions creating disability are examined.

The choices people make in living with chronic conditions and their strategies for coping and adapting in the lifeworld have gained currency in the research domain. As a consequence, the “active” choices in living with chronic conditions and the reasons for the choices made has become a focal interest. The outcomes of personal

experience research has served to inform clinical and theoretical concerns as well as inform and challenge policymaking (Thorne, 2002, et al). Furthermore, it has also created new theory which has informed professional education across disciplines.

2.1.1 Experience as a thoroughfare: body, Self & society

Personal experience research has been interested in diverse topics across a range of chronic conditions. I do not discuss specific studies because they have little direct application in the context of this study. However, the emerging conceptual issues from these studies have relevance here. In my analysis it appears that personal experience research has potential for illuminating the dialectic between the body/impairment, Self and Society. It is this dialectic which I have termed “experience as a thoroughfare between body/impairment, Self and society,” that forms an important part of the theoretical landscape of this study. Stuttering is an “impairment” or phenomenon lived by an individual in a social world. Whilst this interpenetrative understanding of personal experience is desirable, research studies I reviewed appear to gravitate in one of two directions. The first drifts towards an emphasis on body/impairment and self-relationships with marginal attention to the social issues shaping experience, thereby retaining a medicocentric orientation. The second pull is in the direction of Self and society, with little emphasis on the body/impairment dimensions foregrounding the social dimensions of experience.

The personal experience of body/impairment dimensions remains of interest particularly to researchers who have clinical interests. They argue that research about how people experience the bodily dimensions of chronic illness provides a more in-depth subjective understanding of how such disorders are experienced. Numerous studies are dedicated to exploring how subjects experience a particular phenomenon such as head injury (Nochi, 2000); epilepsy (Reis, 2001); arthritis (Dildy, 1996); asthma (Adams, Pill & Jones 1997); aphasia (Kerr & Lacelle, 2000); hearing problems (Perry, 1996); cancer (Coward, 1990; Mathieson & Stam, 1995); multiple sclerosis (Quinn, Barton & Maglivi, 1995; Robinson, 1990), as well as stuttering (Crichton-Smith, 2002; Petrunik & Shearing, 1983; Sue-O’Brien, 1993). These studies are driven by an interest in the subjective experience of the phenomenon of the illness or disorder by gaining insights into the “inner” world.

However, this emphasis runs the risk of retaining a medico-centric orientation because it illuminates mainly the biological/impairment dimensions of the experience.

In this way we may gain a better understanding of how a particular condition such as epilepsy, cancer, arthritis or stuttering is experienced. It is limited because the social dimensions glide out of analytical view, creating a view of personal tragedy of the individual as victim. Frank (1995, 2001), in reviewing medical narrative literature, has cautioned that whilst admission of subjective meaning is celebrated, the stranglehold of medical centricism with emphasis on body/impairment prevails. As a consequence, research subjects are cast into single, fixed subject positions as patients only, allowing the experience to be told from a passive role of one living with disease/disorder stifling creativity (Frank, 2000a) I have offered similar critique with stuttering research. Frank, (2000a) argues that because research is often directed by the medical/clinical researcher who has an interest in the subjective dimensions of impairment, coping strategies and experiences of treatment, there is the risk of discounting lifeworld experiences which are meaningful for the participant.

Moreover, the emphasis on impairment/ body dimensions restricts an understanding of the moral dimensions of the illness/disability experience (Frank, 1997). Frank (1997) explains that the moral dimension of experience is on a different plane to the medical aspects. Within the context of illness/disability, the moral plane of experience responds to the question "Who must I become to resolve this dilemma?" (May, in Frank, 1997), in stark contrast to "What do I do to live with illness?" The crisis generated by impairment is regarded as a moral dilemma because there is often no "good or right" choice and therefore one must live with the consequences of the actions taken. Frank (1997, 2001) explains that explorations of the moral dimensions extend our understanding of "potential consciousness". Researchers can begin to understand the value of imagining new parameters when living with chronic illness. These dimensions are often neglected in the research frame.

The foregrounding of impairment or disorder dimensions have been strongly contested by disability activists. They have taken a firm position in suggesting that the body/impairment should not be the central focus of the personal experience research, and they politically seek to exclude the emphasis on the body/impairment dimension. They argue that endorsing the inclusion of body/impairment results in a medicalised understanding of disability while masking the social realities which create disability (Oliver, 1990). Shakespeare (1992: 40) explains "to mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing evidence that disability is really about physical limitations after all".

Another issue which emerges in the literature is the ontological status of the body/impairment or the notion of reality. Bodily dimensions have received variable interpretations ranging from a fleshy, organic entity, to a discursive product of disciplinary technologies of power and knowledge, to a physical vehicle of personhood and identity (Williams, 1999). In the current swing of the debate led by medical sociologists, there is a strong suggestion that despite the many diverse interpretations of body/impairment, it should be retained as “real” within a broader frame of critical realism (Bury, 2001; Williams, 1999). Bhaskar (1989) strongly argues that the body is a “real” entity. It exists independent of our knowledge or perception of it. He criticises postmodern and constructionist orientations because they conflate *what is* with *what is known* about. Bhaskar receives support from Bury (2001) and Williams (1999), who advocate that the body/impairment exists, regardless of how we choose to interpret it. In the context of this study, I concur with their view that stuttering is a “real” phenomenon. It exists as a “phenomenon” although the interpretations we bring to understanding it may be multiple.

However, in making this suggestion, Bury (2001) and Williams (1999) also retain the view that a critical orientation should simultaneously prevail. Freund (1988) makes a strong case for understanding the *socialisation* of the body/impairment. He explains that society decides how to interpret bodies and impairment. Society, through its value system, decides how to interpret women’s bodies, phenomenon or impairment, the colour of skin. Therefore, an “impairment” or phenomenon like stuttering could take on multiple meanings ranging from difference, to pathology, to disability, and is largely dependent on how it receives meaning within social contexts. The point I want to emphasise in agreeing with Freund is that social interpretations of a phenomenon (such as stuttering) or impairment, often become naturalised. We accept them as intrinsic or natural when they are in fact social constructions such as women are “naturally” weaker or old age is accompanied by lack of energy. *The body/impairment therefore is “real” but not a neutral entity because it receives meaning through society.* In the context of this study it is important to understand how stuttering as a phenomenon is understood and the meaning it receives through society. In this study I therefore explore participants’ experience of the phenomenon of stuttering, including personal bodily dimensions, but also seek to retain my understanding within a broader social framework.

Inserting the Self into personal experience research

The insertion of the Self or "I", into the research dialogue makes a significant contribution because the individual's experiences receive illumination (Reissman, 1990). Sacks (1995: 25) explains the value of the self-story:

Ask not what disease the person has, but rather what person the disease has. The answer to the first question is a monological chart. The answer to the second question will always be a story. Unlike disease, no two people will have the same. And every person has a story to tell.

The consequence of inserting the Self into the research equation is that it *breathes life and people* into the research process. Research becomes "peopled" by admitting the multiple body, social, emotional, economic dimensions of experience. The Self as a medium or lens through which experience unfolds, has become pivotal in understanding experience of personal impairment in the lifeworld. In the literature, therefore, Identity and Self have become useful lenses through which to gain access to personal experience. Sacks (1985) asserts that the study of identity and disease cannot be disjoined in personal experience. In order to understand how an impairment is experienced, he argues that we must understand who the person is, his identity. I retain this emphasis as central in this study. Experience varies across time, people and contexts and therefore the Self as unique in the context of a biography. Through the Self, the complexities of the unique biographical makeup, the dimensions of impairment and social issues are brought together, illuminating the nuanced nature of personal experience. For Sacks (1990), this view stands in contrast to the view of modern medicine:

...yet, modern medicine, increasingly dismisses our existence, either reducing us to identical replicas reacting to fixed stimuli in equally fixed ways or seeing our disease as purely alien and bad (Sacks, 1990: 228).

The Self/Identity has been used as a conduit for understanding dimensions of living with chronic illness/disability. In particular, there has been an interest in the formation of identity after biographical disruption such as head injury (Nochi, 2000), cancer (Mathieson & Stam, 1995), and spinal cord injury (Yoshida, 1993), as the basis for understanding how participants cope and adjust to illness. The actions people take depend on how they construct their identities and these cannot be delinked

(Charmaz, 1995a; Morse, 1997). I briefly review two such studies to illuminate the issues relevant to this study. A dimension of critique levelled at such studies has been that the understanding of Self as medium focuses either on the *process* or *outcome* of self-reconstruction as a means of illuminating experience, and how participants cope or adapt to chronic conditions.

Research on some chronic conditions (Bury, 1982; Corbin & Strauss, 1987; Williams, 1993), has been interested in the process dimensions, that is, on the continuity of the Self prior to illness and integration of new aspects of Self after the biographical disruption. However, the outcomes of identity reconstitution lack specificity. In contrast other researchers (Charmaz, 1987; Fontana & Smith, 1989; Orona, 1990) have considered the outcomes of identity reconstitution. Charmaz (1987), for example, conceptualises these outcomes or identity goals in a hierarchy comprising different identity levels: supernormal identity, the restored self, the salvaged self and the contingent self. She suggests that the individual may move up or down the identity hierarchy as the formation of selves is influenced by relationships within a social world. The individual's preferred identity or identity goal is constantly influenced by evaluation, negotiation and confirmation by significant others.

Yoshida (1993), examining the consequences of spinal cord injury as a chronic disability for Self and identity, makes a useful contribution in considering both the "process" and "outcome" of self-constructions, also a consideration in this study. She suggests that research frameworks should consider both the process and consequences of chronic impairment for Self/Identity. She makes a strong case for non-linear models of identity reconstruction in understanding experiences of disability and also asserts that there must be a consideration of how disability merges with the non-disabled Self. She makes a significant contribution in suggesting that there is more than one unitary disabled identity formation occurring in the context of a single story. The structure and organisation of the emergent Self may change as the individual interprets and reinterprets who he is in the context of himself and society. She proposes a pendular construction of Self detailing the process of the pendulum swing and the outcomes, highlighting that variation across time and situation.

A further point of debate has been around the idea of a public (social identity) versus private (personal identity) Self. Morse (1997) suggests that Charmaz's (1987) work is incomplete because it limits the scope of work to the public self while simultaneously neglecting the private self. The inner self is unique to individuals who possess the

cognitive capacity to imagine their appearance and feelings in particular ways. They can create a private self which others may not have access to. It may be obliterated as the public self is foregrounded. As an example, she finds that those with "hidden" disabilities such as multiple sclerosis are frequently in conflict because they maintain an able public/social identity, while the suffering of the private self remains masked. Morse (1997) therefore considers how the individual responds to threats to the Self at a personal/ private level. She presents a five-stage theory of how individuals respond to identity threats coupled with an analysis of their responses and strategies to cope at different stages of illness. My concern is that neither the public nor the private self on their own is sufficient, because both the public and private selves contribute to narrative identity formations. Therefore, I use the term "self-identity" which I problematise later in this discussion.

Whilst these studies have diverse interests they highlight the *centrality of the Self* as a means of understanding how people with chronic conditions reconfigure their identities and *cope or adjust to illness/disability*. In this regard there is a significant contribution in framing the person with chronic illness as agentic and active. Sacks (1995: xiv) responding to the moral or agentic dimensions of personal experience, maintains that

sickness implies a contraction of life, but such contractions do not have to occur. Nearly all my patients, so it seems to me, whatever their problems, reach out to life - and not only despite their conditions, but often because of them, and even with their aid.

Although Sacks has been criticised for offering only his "paternalistic" interpretation of patients' problems (Mergenthaler, 2000), he has nevertheless raised the issue of agency that has traditionally received little emphasis in medical literature deriving from a technical rationality. In this study, I want to explore the experience of participants from a perspective of being active rather than passive.

The self-construction also offers insights into *power relationships and social structure* (Kelly & Dickinson, 1997). In the account of "I", the individual also shares how he sees himself in relation to others, with regard to dimensions of power. These personal offerings provide a window through which to understand dimensions of power and oppression in societies and advances a context to understand the participant's choice of action. Medical narratives have illuminated critical insights on

the potential powerlessness of disabled people in an "able" society. Within the process of self-construction participants, the self is objectified. The Self can be examined as to whether it has changed and how it may have changed (Kelly & Dickenson, 1997). This introduces an evaluative dimension to experience through which participants can explain and justify to themselves and others their actions and choices. In this way the Self is reflexive within a social context (Williams, 2000), and is able to constantly evaluate and problematise its change or development, over time.

In summary, the literature I have presented thus far has direct application to this study. Like other researchers, I have also chosen self-identity as a medium through which to gain access to lifeworld experiences of stuttering. Furthermore, I have chosen to consider the process and outcome dimensions of self-identity formations of participants who stutter. Because issues of self-identity formations are central to this study, I revisit the theory of self-identity in greater depth in creating a theoretical landscape. In my review of literature on self and chronic disability, it has also become apparent that the literature by and large has an adult-centric focus (Bury, 2001). The biographical disruption in most instances occurs during adulthood and the changes during adulthood are explored. Stuttering in comparison begins in childhood, and therefore the formation of identities must be examined from early on in childhood.

Social landscape of experience

The personal experience of chronic impairment unfolds in a social landscape. The disturbances of the body/impairment therefore must occur within a theoretical scheme which links dimensions of social power with disease (Radley, 1993). Within the accounts of personal experience, the *social must be illuminated*. What constitutes the social and how it unfolds in personal accounts is debatable. It raises a host of issues about how we see the world, the distinctions between society and Self, the specific geographical, historical and political contexts, the social discourses available, institutional power and the local world in which experience unravels. It is at this interface of disability experience that the macro-micro, structure-agency, individual-society debates come into play. All of these issues are, in themselves, historically unsettled debates (Williams, 1999). I review them with the understanding that they are incomplete, but nevertheless warrant discussion.

Similar to the debates about the ontological existence of the body, the debates in the literature focus on the ontological status of society (Kelly & Field, 1996). Williams

(1999) again makes a strong argument for retaining the social within a frame of critical realism. In short, he suggests that the social exists. He also makes a convincing argument that society and the individual are not the same although they are mutually-constitutive and that they should not be conflated. This allows structural-agency dimensions to be examined in greater detail without one collapsing or subsuming the other. This attempt to resist conflation is also supported by Skultans (1999), who argues that the personal can never be completely colonised by the social, particularly when the social terrain itself is fragmented and calls for conflicting allegiances. Within this understanding that society is "real", it is also important to consider that society is morphogenetic by nature. It has the capacity to change form and shape. Social systems therefore remain open and are "peopled" by agents who are reflexive and creative (Archer, 1995). Social structures may be transformed or reproduced through consciousness and critical praxis of social actors, both individually and collectively. It is this view I advance in this study.

Disability theorists and activists have actively promoted an understanding of experiences of disability in the context of a social world. Oliver (1990), in taking a radical step in rejecting a body/impairment emphasis of disability, argues that the disablement or consequences of impairment have everything to do with society, its barriers and prejudices, which mitigate against full participation for those with disability on equal terms. The research emphasis has therefore been directed to the political, economic and social conditions of living with disability (Barnes, Mercer, Shakespeare, 1999; Corker, 1998,1999). As a consequence there has been a shift in understanding hearing impairment as difference rather than pathology. Research in the culturally Deaf population is a good example of how participants do not define themselves from a pathological perspective, but rather as a linguistic minority (Corker, 1998).

It is at the social interface that People With Disabilities share similar concerns of being constructed as an epistemological Other (Perry, 1996). Hearing impairments or stuttering, being black, female, gay - those who do not meet a certain norm in society are considered "Other" in societies. Many researchers and theorists have used Goffman's (1963) theory on "spoiled" identity to theorise experiences of disability or "Otherness" and management strategies.

A person who is stigmatised is a person whose social identity or membership to some social category, calls into question his or her full humanity - the

person is devalued, spoiled or flawed in the eyes of others (Crocker, Major, Steele, 1998: 504).

Stigmatisation is a social construction and therefore varies across historical periods and social contexts. As a construct, "stigma" involves notions of deviance and prejudice which serve to define one's character and identity in an *essential* way. This has devastating consequences for emotions, thought and behaviour for those who stigmatise as well as stigmatised people themselves. In such research contexts the researcher is obliged to problematise or de-naturalise (Wray-Bliss, 2002) the constructions of the Other within a sociocultural frame. He problematises and questions why women, PWS and gay/lesbian people have been cast as Other. Researcher must be cognisant of social processes such as normalisation (Foucault, 1977), including their own biases, leading to constructions of Otherness. The researcher must be cautious because he has the potential to reinforce and perpetuate such domination especially when writing about a group to which they do not belong (bell hooks, 1989).

Researchers have a moral responsibility to remain vigilant to issues of political oppression, repression and agency within accounts. This requires an interrogation of forces occurring in everyday life which shape experience in a *political* way. Personal and social truths can thus be juxtaposed, and researchers can reveal how they are inextricably linked, thereby offering potential for "new" truths to gain currency. As a means of including social issues as mandatory on the research agenda, People with Disabilities in some contexts are rightfully insisting that they are part of a knowledge production enterprise which concerns their lives (Barnes, Mercer, & Shakespeare, 1999; Shakespeare, 1994). It is a stance I agree with. I therefore consider the participation of PWS as critical in illuminating social issues which have been neglected in stuttering literature.

"Othering" (Fine, 1998) does not occur only on the basis of impairments, but also on dimensions of race, gender, sexuality, class or education. However, in researching experiences of disability, there is a tendency for neat, clean and categorical understandings of identity to emerge, of one who is disabled. This masks the complexity of the identity formations of PWD. The actual experience, in contrast, is frequently embedded in other "disabling" social realities e.g. being female or poor (Frank, G, 2000), creating a scenario of multiple oppressions. Frank, G (2000) suggests that some research studies neglect these multiple dimensions in

foregrounding only the single identity as disabled. This fails to draw together the multiplicity of social dimensions which combine to shape identity and experience.

Postmodern influences have become more popular in the 1990s, with identity research on People with Disability (Corker, 1998; 1999; Watson, 2002). As a consequence, understandings of People with Disability have been constructed in multiple ways in a social landscape. Subjectivities are fluid, socially-constructed, interrelational and political (Wray-Bliss, 2002). Instead of viewing race, gender, education, language and disability as discrete categories, it has become possible to consider them as inseparable aspects of a system, an intersecting nexus, through which we can understand how people experience impairment.

The traditional neglect of multiple subjectivities has two dire consequences. On the one hand, it runs the risk of failing to understand multiple or simultaneous oppressions such as being a female with disability. On the other hand, by relying on a singular construction of the PWD, it assumes that anyone who has an impairment must experience it as a disability, thereby masking potential (Watson, 2002). Foucault (1977) argues that instead of compressing diversity of selves, we should celebrate heterogeneity that creates alternative possibilities, freeing us from unitary ways of understanding ourselves. It is within the cultural and intellectual movement of postmodernism that various approaches (poststructuralism, social constructionism, critical psychology) to understanding people as social beings has flourished (Corker, 1998).

In personal experience research social dimensions have emerged in multiple ways. For example the influences of *historical, sociopolitical and political* forces shaping experience have been foregrounded by some researchers. Skultans (1999) explores the relationship between social and political contexts of living through personal experience data. She traces the experience of a Latvian countrywoman during the Second World War and reconciles how a significant historical event became annexed to the body. She uses the dynamics of the personal-social interface to explain the development of mental illness. Embedded in the story are examples of cruelty of the government policy on pregnant women and hard physical work took priority over reproduction and childrearing. The high rates of alcoholism among men during war-time and the nervous exhaustion of soldiers and their mothers contributed to illness. Skultans (1999) links public events to personal lives and explains their repercussions on health. Similarly in South Africa, the impact of conditions of living in an apartheid

system and worker migration policies have contributed to HIV-AIDS (Campbella, 1997).

Williams (1993) examines how *value systems and social discourses* in society are represented in personal experience in the study of "Mrs. Fields", a sixty-two year old widow who suffers from rheumatoid arthritis. Her experience unfolds in a British town at a time when the values of Thatcherism and Protestantism prevailed together with an individualistic ideology of health within a welfare state. The individual ideology leads people to blame themselves for their misfortunes, suggesting that they should be responsible for managing their problems without considering how their private lives are influenced and shaped by structures of power and privilege in society.

Against this background Mrs Fields' story illuminates the influences of the medical model, as she relinquishes control of her body to the doctor. Despite suffering the consequences of a severe ailment, she feels compelled to assume strategies which are guided by a broader view in society of health as a virtuous state, that is, being in good health is the right way to be. As a consequence, her pursuit of virtue represents the interconnections between herself and society as dependence, uncleanliness and indebtedness become primary themes. She makes choices which allow her to remain independent to the best possible extent, so that she does not become an encumbrance to her family. Despite her limited physical resources, she is driven by the need for cleanliness, as being dirty is a sign of individual loss of control and disorder. Similarly, her need to foster independence and struggle to remain debt-free is driven by the influence of "Thatcherism", which suggested that taking care of money is a characteristic of being a competent human being. While from a clinical medicine point of view Mrs. Fields appears to be coping well, her real battles unfold at the social interface.

Kitwood (1993) explains how *dominant discourses in society can shape how people come to interpret chronic phenomenon*. He uses the example of dementia to trace how its understanding has become medicalised via powerful social processes of professionalisation and medical science. He argues that while there are major problems with how dementia has been constructed, the most basic is that little attention has been given to the basic relationship between the brain and the mind. However, institutional prestige underpinned by medical constructions of dementia coupled with material interests, have created a façade of "truths" difficult to contest. As a consequence of powerful social processes, the medical constructions of

dementia have become naturalised and constructed in personal stories as a medical condition. However, the experiences in the lay world frequently create differing and conflicting views which stand in opposition with the dominant discourses. It becomes important therefore to understand the influence of dominant and competing discourses shaping personal experience of chronic conditions.

Although the theoretical issues surrounding the social dimensions of personal experience have been discussed here, I emphasise that the personal accounts of illness experience unravel in everyday worlds as first-person stories. These accounts have traditionally not been attended to because they are mundane. However, it appears that via the scrutiny of these mundane worlds, the impact of macro-events, social discourses and ideologies, life events receive illumination. It is often that such issues are neglected. As Bauman (2001: 121) explains, "good lighting is true blindness: one does not see what is all too visible".

To conclude this part of the discussion, I quote Freund (1988: 857) as a summarising statement regarding the nature of experience with which I concur.

It is important to understand that I am not merely suggesting that the mind, body and society are *connected*, but rather that they dynamically interpenetrate. Furthermore, at different "moments" the process of social construction of the body is significant, and that at other "moments" it is the impacts of such bodies on social life that must be considered. There is constant interplay between the psyche, soma and social existence. What occurs on a social plane affects the body and vice versa.

It is against this backdrop, retaining the notion of experience as a thoroughfare between body, Self and society, that I explore and theorise the experiences of stuttering. I continue to create the theoretical frame by expanding the discussion on self-identity formation over time.

2.2 Theorising Self-Identity formation

In framing my critical questions, I have chosen self-identity formation as a prism through which to explore my interests in experiences of stuttering in the lifeworld over time. The repetition between aspects of this discussion and the preceding literature is unavoidable. However, I try to keep this to a minimum. For the purposes of this study

a problematisation of issues of self-identity formation and social action is necessary. There has been a veritable explosion in the literature around the concept of Self and identity. This is evident in the many theories and research studies across disciplines and particularly in psychology and sociology in the past five decades (Bendle, 2002; Brubaker & Cooper, 2000; Castells, 1997; Erikson, 1959; 1968; Giddens, 1991; Goffman, 1963; Hall, 1996; Hermans, 2002; Mishler, 1999; Polkinghorne, 1996; Samuel, 1998; Somers, 1994; Woodward, 1997).

In this study I am interested in how and why participants form understandings of themselves, having lived with stuttering in a changing social world. Self-understanding includes a combination of the personal, inner, intrapsychic dimensions as well as the understandings they create in a social landscape, that is, their private and public constructions. This approach to self-understanding, or *narrative identity*, brings together the multiple dimensions of experience within a single story. The focus on self-understanding places emphasis on how the person creates an understanding of himself, in contrast to an externally-generated understanding. To accommodate the complexity of narrative identity and to foreground self-understanding, I use the term self-identity in this study. In appropriating the narrative theory of identity and Self, I draw on literature from two primary sources, Somers (1994) & Mishler (1999). Mishler (1999), from a psychology background, offers a theoretical basis for a life history perspective to the study of identity formation which is useful here, because it links the “what and how” of identity formation over time. Somers (1994) from a sociological background, brings into the discussion theories of social action which connects the issue of identity formation with how people act. To these I add other relevant dimensions and issues where appropriate.

A brief historical diversion about identity theory is necessary here to understand why self-identity is important, especially in contexts like South Africa, which are rapidly changing. The formal studies of self-identity in Western societies historically appeared in the 1800s as there was an erosion of religious teachings accompanied by the rise of Romanticism (Bauman, 2001; Bendle, 2002). People began to fashion integrating worldviews of themselves as the value-consensus nature of society was disintegrating (Bendle, 2002). Differentiation on the basis of ancestry, gender and religion was delegitimised. It is therefore not surprising that as social change processes have intensified in the twentieth century, a period described by various theorists as “liquid” modernity (Bauman, 2001) or “high” modernity (Bendle, 2002), there has been an explosive interest in identity theories and research. The literature

on identity formations is symptomatic of the rapid pace at which the world is changing, creating increasing impetus for questioning who we are (Bauman, 2001).

Over the past decade, narrative as a way of knowing, (Somers, 1994) in the human and social sciences has created opportunities to approach the study of identity formation and social agency empirically by bringing together at once the temporal, relational, macro-structural, cultural, institutional, personal, cognitive and emotional dimensions. Such emphasis avoids categorical rigidities in locating *identity formation* "in overlapping networks of relations that shift over space and time" (Somers, 1994: 607). When people create stories of themselves they are likely to occupy multiple subjective positions, giving way to the notions of multiple subjectivities, thus leading to the notion of identity formation as multiple and fluid. Mishler (1999) uses identity as a collective term to refer to the dynamic organisation of our sub-identities which may conflict or align with each other. "We speak ...or sing ourselves in a chorus of voices" (Mishler 1999: 8). In agreement, I use the notion of self-identity as "heterogenous" a means of highlighting multiple subjectivities.

Based on the idea that the self-identity is heterogenous, I also take the position that various *self-identities are in dialogue with each other* (Frank, A.W, 2000b). There are always intrasubjective exchanges between self-identities or self-understandings in dialogue with each other. Agreements, oppositions, disagreements, contradictions and integrations are inherent as they are spawn from different beliefs and experiences (Hermans, 2002). The relationships between the self-identities are characterised by dominance and social power. Samuel (1998) uses the notion of the "multicultural" Self in teacher identity formations, to explain the multiplicities of Self as well as inherent power dynamics influencing identity formations. Therefore, dialogic interchange and dominance are intrinsic features of heterogeneous self-identity formations. For one self-identity to be more dominant or powerful, it has to be made more actual, real, stronger, while the others must be more or less suppressed (Barresi, 2002). However, because the self-identity is dialogic and dynamically fashioned, it does not mean that it is necessarily unstable or stable. It has the capacity to be flexible as well as stable (Valsiner, 2002) over time.

Castells (1997) explains that whilst identities may be plural, the concept of identity should also be differentiated from roles and role-sets. He explains that people may have many roles, for example, as mother, neighbour, basket-ballplayer and smoker at the same time. He argues that identities are *sources of meaning* that actors

construct for themselves through processes of individuation. Identities only become identities when social actors *internalise* them as such, and therefore identity as a construct has become a useful lens through which to understand experience. While identity is organised around personal meaning, role is orientated towards function. Although identity constructions may coincide with social roles, identities are stronger sources of meaning than roles. While dominant social structures may be a force shaping identity, it is only when the *individual internalises such meaning that it constitutes identity or contributes to a process of identifying*.

I consider formation of narrative self-identities as always “*in process*” One is always in a state of becoming, as the selves interact, over time. Cortazzi (1993:13) emphasises the historical and “process” nature of the Self

The self then, the self now recalling then, the self now interpreting the self then from the present self's perspective, the self thinking of future possible selves, a possible future self looking back to now, to the present self seeing it as in the past.

I use the term “formation” in this study to reinforce the process orientation between present, past and future, but also to shift away from the notion of self-identity “development” which has traditionally been associated with stage models of development. The later emphasis in the study on human stage development has been largely influenced by positivist research across Psychology, Sociology (Mishler, 1999) and Speech-language Pathology (Pillay, 2001, 2003). Mishler (1999) explains that while the early theories of Piaget, Erikson and Freud on child development and identity formation were based on case study methodologies, they were not retained because they were not considered “scientific” within a positivist tradition. The shift to traditional, variable- orientated approaches to the study of identity formation has encouraged classifications and categories (Polkinghorne, 1996), reinforcing orderly, universal, progressive stage-development understandings of identity formation over time (Corker, 1999; Mishler, 1999).

The problem with the universal orientation is that it is not universal. Most often, the data is generated in minority, Western world contexts and are presumed to be universal (Burman, 2000). However, in the contexts of increasingly diverse, complex childhoods and life courses, such models have little application in understanding the individual. The discrepancies become evident when longitudinal and cross-sectional

studies on the same population reveal different patterns of development (Mishler, 1999). Qualitative studies, narrative methodologies and case-based studies are increasing in popularity across disciplines. The emphasis on inter and intra-individual variability has emerged. The tracking of the individual case stands in contrast to the stage development model, which most often does not have utility in understanding the individual child (Mishler, 1996). Therefore, a *case-centred* orientation to understanding self-identity formation *without intention to suppress variability* is intended here. I consider the formation of individual trajectories over the life course and seek to understand how self-identities are formed in the context of the single case over time.

Although change is a feature of everyday life and perhaps the most salient characteristic of living entities, researchers invest in seeking the threads of continuity (Mishler, 1999). This orientation to change is underpinned by a mechanistic view of development, where it is assumed that each event leads to a succeeding event within a sequential chain. Change is posited as gradual and predictable. In contrast, researchers within a narrative tradition (Bateson 1989; Becker, 1997; Josselson, 1996) suggest that lives are perpetually conflicted and interrupted, and that therefore, a single and continuous life trajectory is unlikely. Becker (1997) has argued that the notion of continuity has a culture-specific shape in western societies where the ideas of life course emphasise linearity and continuity. Based on metaphorical images like “progress” and “development”, “gain and “loss”, there is the assumption that development is orderly and progressive.

In contrast, Becker (1997) has suggested that real lives are more unpredictable than the cultural ideal. She conducted case-based analysis of various life disruptions in ethnic minority and Western subjects in America. The disruptions included infertility, midlife crises involving job losses, career changes, divorce and late life disruptions (stroke) pertaining to illness and aging. She demonstrated that the disruptions and discontinuities are features of changing identity formations. She emphasised that identity trajectories are not even, continuous or gradual. Similarly, Josselson (1996) studied the identity formations of women between 21 and 43 years of age and concluded that they were constantly revising themselves, and that there were no fixed sequences or stages in their identity pathways.

Mishler's argument for discontinuity is linked with his emphasis on variability. In a study of work identity (Mishler, 1992), he explains some identities as “detours” or “off-

line" in relation to the identity as worker. In contrast, he describes others as having "on-line" identity formations as they return to an earlier interest with respect to their work. Discontinuities and disjunctures along career paths were more typical than unusual and therefore placed discontinuity as central in the study of identity formation. This offers the opportunity to include diversity and change into the study of identity formation without being restricted by a search for continuity (Mishler, 1999).

Other researchers (Conrad, 1987; Yoshida, 1993) of medical backgrounds have also supported the stance to place discontinuity as important in the studies on identity formation. Conrad (1987) recommends the use of the term "trajectory" to suggest that change in the context of illness is neither linear nor orderly. While I think that continuity is possible within a single life, Mishler's arguments and the empirical data (Becker, 1997; Josselson, 1996; Watson, 2002; Yoshida, 1993) are far more convincing and appealing. I therefore use the term "trajectory of self-identity formation" with intention to foreground the notions of *non-linearity and discontinuity*.

The study of identity formation must occur within *social and historical contexts*. It seems fairly obvious that who we are cannot be separated from the worlds in which we live. However, this has not always been the case given that research within a positivist tradition has separated the study of the individual from the world in which they live. In models of identity formation like Erikson's, the processes of identity formation have been restricted to the individual (Mishler, 1999). The stages and conflicts are regarded as intrapersonal, without consideration for how the social landscape shapes such processes. In contrast, disciplines like social psychology are premised on the assumption that who we are is shaped by social contexts, and researchers argue that identities are embedded in societal structures, practices and processes (Howard, 2000). In the domain of social psychology, the issues of identity formation as a *relational process* occurring on a social landscape have been researched. From a social psychology perspective, for example, social cognition and symbolic interaction theories form the theoretical underpinnings for the study of identity. Although they differ in theoretical orientation, they share the common assumption that identity formation has a social basis.

There have been numerous studies dedicated to understanding social identities. Among these are the studies of ethnic, sexual, gender, disability, age and geographical identities. The politicised nature of social identities and social forces shaping identities has been explored. Gender studies have become most prominent

among social identity studies. They emphasise contextual influence on the salience of gender identities (Ely, 1995) in contrast to the influence of biological or personality factors. These studies illuminate how hegemonic social forces have shaped the identities of women and contributed to a politicised understanding of social identities (Howard, 2000).

As already mentioned, many studies of identity have been based on single social positions of race, gender, class, disability and age. However, there have been repeated calls for the understanding of social identity to include an analysis of how identities intersect and overlap, to render the richness and complexity of experience. In disability studies of identity, the singular notions of identity have political currency but these studies tend to mask the complex issues of being women and disabled, Black and disabled, or Black, poor and disabled. In narrative studies of identity, postmodern/poststructuralist orientations (Crenshaw, 1997; Freitas, Kaiser, Chadler, Hall, Kim & Hammidi, 1997; Reid & Comas-Diaz, 1990; Rust, 1996) have considered the *intersectional nature of identity* and collectively challenge fixed, dichotomous, unified notions of identity. Rust (1996) considers the intersections between sexual and ethnic identities with regard to bisexuality. She argues that whilst bisexuality may be an acceptable identity in some ethnic groups, bisexuals in these marginalised groups manage these interacting oppressions through creative reinterpretations of bisexual identity. Crenshaw (1997) argues that intersectionality must consider structural disadvantages and multiple (dis)advantages.

Somers (1994) *relational and network approach* to identity formation is useful here. She argues that all identities exist only within the context of relational and cultural matrices. They should not be analysed outside of these matrices. In supporting a social and relational formation of identity, she contests the notion of the totalising concept of society because societies change and are plural. Instead, Somers (1994) uses the term “relational setting”. This construct is useful in biographical research because each life is situated within a particular relational setting and a particular society. Within a relational setting (society), there are (changing) patterns of relationships among institutions, public narratives and social practices, which are appropriated into constructions of self-identity. Therefore, self-identities are necessarily unique constructions.

Somers (1994) also asserts that narrative identity can only be understood in the context of empirical inquiry *without a priori assumptions*. This serves the purpose of

divesting the narrative of particular normative implications as people are free to create their stories from their perspectives. Therefore, a PWS is free to create his identity which may stand in contrast to the normative expectations in society. Baressi (1994) in Hermans (2002) reinforces a related point by explaining that when two people take on the same subject position, such as “father”, the experiences will never be the same. The same applies to PWS.

In the context of Somers’ notion of relational settings, it is important to illuminate the nature of the particular relational setting in the context of individual stories. My interest is in questioning how the relational network in which one lives shapes how one forms an understanding of oneself, in relation to stuttering. It is a complex task to delineate what a relational setting might be like because these settings are in themselves dynamic. However, it would seem irresponsible for me to dismiss the issue without discussion. The points I discuss are intended to problematise the concept of the relational network by presenting a broad brushstroke picture of issues relevant in South African society, but this painting is by no means exhaustive.

What would constitute a relational setting, a social world, in the context of an individual life in South Africa? As a means of theorising the dimensions of the relational setting, I suggest that the individual’s relational network is embedded in a larger and particular society, which is making a significant and rapid political transition. At a *political level*, South Africa post-1994 is making a transition from apartheid to democracy. Within this transition there has been a questioning of who we are, as our identities are officially no longer shaped by race alone. In the transitional period all sectors of society have been challenged to reorganise themselves in the interests of equity, democracy and justice. As a direct consequence, the combined influences of the medical model and apartheid have come under scrutiny as society considers other models in the interests of becoming more equitable. The issues of those who have been marginalised, black people, women, children, poor and disabled have come to the fore and have been actively debated at public levels. Society is not homogenous and South African society in particular is characterised by diversity. People are of diverse geographical, ethnic, race, education, class and religious backgrounds. The participant’s local worlds are situated within this grander landscape which may shape identity formations in particular ways.

However, South African society is also part of a larger, historical, globalising world, and these influences may also be evident in the local social networks. The nature of the world is complex, diverse, political as Castells (1997, 1-2) describes:

Our world, and our lives, are shaped by the conflicting trends of globalisation and identity. The information technology revolution, and the restructuring of capitalism, have introduced a new form of society - the network society. It is characterised by the globalization of strategically decisive economic activities. By the networking form of organisation. By the flexibility and instability of work, and the individualization of labour. By the culture of real virtuality constructed by a pervasive, interconnected and diversified media system. And by the transformation of material foundations of life, space, and time, through the constitution of a space of flows and of timeless time, as expressions of dominant activities and controlling elites. This new form of social organization, in its globality is diffusing throughout the world, as industrial capitalism and its twin enemy industrial statism, did in the twentieth century, shaking institutions, transforming cultures, creating wealth, inducing poverty, spurring greed, innovation, hope whilst simultaneously imposing hardship and instilling despair. It is indeed, brave or not, a new world

Against the background of a complex “glocal” (interaction between local worlds and global trends) world, everyday lives are also structured in particular ways. Institutions of society, including families and significant people, shape what happens on a daily basis. It is through social engineering that children are educated at schools, that there are hospitals and clinics to treat sick people and that criminals are jailed. These institutions in turn reflect society’s dominant value systems in their modes of practices. We can also gain an understanding of how social institutions operate through discourses available. For example, people in society may talk about stuttering as an illness or disability in a way which also offers insights into how these issues are understood in society.

Bauman (2001) asserts that we should also consider the impact of broader projects of modernity and liquid modernity (Marotta, 2002), which influence how we live on a daily basis and form identities. Bauman 1991, in Marotta (2002), chooses the term “liquid modernity” rather than “postmodern” because modernity is still alive. However, his analysis of modernity and the construction of boundaries is useful here. He suggests that modernity is about the production of order. Human beings have

become order-seeking beings, and their search for such order is commonly associated with the suppression or exclusion of “strangers” - those who are “Other” (Marotta, 2002). The stranger or Other is one who creates “chaos” and represents a threat to fixed or stable boundaries modernity has established, for example, classifications of race, gender, disability. Dis-Order is a label which could be applied to anyone who breaks the rules or creates chaos threatening social orders and rules. This can range from criminals to people with disabilities or anyone in a particular context sporting “inappropriate” behaviour. The net effect of active ordering supported by processes of classification and construction of boundaries, entails oppression and exclusions, so that only one order remains. How are identity formations shaped where such discourses prevail?

Postmodernity as a self-reflective state of mind challenges the universalistic tendencies of modernity (Corker, 1998). It seeks to recapture the contingent nature of the world and reconsider boundaries, creating a tolerance and celebration of new orders, fluid categories and ambivalence. Even within a postmodern discourse of accepting diversity there will still be “Othering” and “postmodern strangers”. It is an issue with which societies will continue to struggle. While there is no resolution, Bauman suggests that we should not lose sight of the moral responsibility towards those who are “Other” (Morotta, 2002). Where different or counter discourses prevail, how are identities formed?

My assertion is that the dominant and counter discourses and value systems shape how individuals live, for instance, the interest in ordering can be seen in everyday worlds, in the rules we make about how we drive cars and expectations about how we should speak and form identities. Giddens (1991:1) aptly summarises the impact of how social discourses pervades the nature of day-to-day social life and affects the most personal aspects of our experience using modernity, as an example:

“Modernity must be understood at an institutional level; yet the transmutations introduced by modern institutions interlace in a direct way with individual life and therefore with the self”.

How do stuttering experiences unfold in the midst of such discourses and influences?
How are self-identities formed in the midst of social complexity?

While I have introduced the notion that self-identity is being shaped by a social context, the importance of the *body/impairment* dimensions shaping self-identity formation must also be considered. Our understanding of who we are is shaped by our *embodiment*. From her experience with narrative constructions of self, Young (1989:152) explains that:

People are tender of their bodies as if their selves are inhered in its organs, vessels, tissues, bones and blood, as if they were embodied. Embodying the self is an important shift in the context of understanding medical narratives because it installs a Self into the body. Medical science has traditionally engaged with the body without Self. The notion of Self as embodied therefore brings back a humanization of the body and frequently dissolves the traditional boundaries between body and Self.

How does living with stuttering, in an embodied sense, shape one's identity formation? As I have discussed already, impairment and body dimensions are not neutral entities. A body that is black, white, female, male, impaired, able receives particular meanings in society, and has potential to influence the formation of self-identity. Therefore, it becomes important to examine how self-identities are formed in this complex thoroughfare between body/impairment, Self and society.

In crafting an understanding of ourselves at a personal-social interface, we also bring in a *moral* dimension to self-identity formation. In daily lives people craft stories about themselves to retain their moral identities (Gergen, 1994b). The formation of identities therefore must be understood against the backdrop of societal norms and values about what it means to be virtuous. Who we become, or are shaped to become, occurs in the context of what is right and wrong in society, and there is always contestation about what is right and wrong (Frank, A.W, 2000b). Therefore, it may be unusual for an individual to claim to want to become a criminal in a society which may value honesty. Frank (2002) explains that hearing the moral impulse in a self-story is critical because it enables the researcher to become part of a participant's struggle to re-enchant in a disenchanted world. He suggests that when we fail to understand the moral dimensions shaping self-identity formations, we are doomed to pessimism and then we can only "lament what is not" (Frank, 2002: 8).

If our understandings of ourselves are always in process, multiple, fluid and shaped in multifarious ways by life events, our immediate relational networks, social

institutions, values, discourses, our bodies, our intrapsychic and human nature, then, what does this mean for how we act?

2.3 Self-Identity and social action

I have an interest in understanding how and why participants negotiate stuttering in the context of their self-identity formations. Why do they act in the way they do? The studies and theories of identity formation have made significant contributions to understanding social agency (Somers, 1994), by engaging the participant as “active”. In the domain of “identity politics”, there has been a strong shift in emphasis from understanding action in universalist, normative-driven ways, for example, that all PWS act in the same way, to a stance of “I act because of who I am” (a situated, relational identity). This shifting stance offers people constructed as “Other” on the basis of disability, gender and race, to be constructed alternatively and positively so that even those devalued traits come to take on new meaning. The impact of this orientation is evident in narrative feminist studies (Josselson, 1995) which have created a new frame of meaning affording an opportunity to understand why women do not act like men. In doing so, such understandings make a significant challenge to theory which has traditionally defined 50% of the population as abnormal (Somers, 1994). As a consequence, the actions of female behaviour are evaluated on their own terms, thereby transforming otherness into variation and difference.

A situated relational understanding of social action also offers the opportunity to understand the specifics of the context as a requisite to understanding action. This is in contrast to a universalist, essentialist identity which assumes that a woman or PWS will act in the same way regardless of context. Because one cannot make a *priori* assumptions about how an individual constructs himself in a particular relational setting, one equally cannot make assumptions about how he is likely to act. In this study therefore, I consider how and why PWS negotiate stuttering in the context of their identity formations over time.

I attend to the issue of power in understanding social action. Although the issue of power has been embedded in different aspects of the discussion, such as the dominance of social discourses or the competing nature of identity formations, the issue does not belong in any one place in this discussion. I discuss it separately here for conceptual clarity, although it underpins all dimensions of relations influencing identity formations and social action. How people act and form identities is related to

power. In the context of human relations, which are central to identity formations, Foucault (1980) suggests that power is always present. He maintains that in the context of controlling the other, power is mobile and can be modified, it is reversible and unstable but never fixed. He acknowledges that power relations are possible in so far as subjects are free. He notes that states of domination can also exist and that power relations can be fixed and perpetually asymmetrical. As a consequence, there may be an extremely limited margin of freedom influencing how people choose to act.

Foucault (1980:98) describes power as a complex strategy, affecting how we choose to act. The nature of power is such that it is:

Never localised here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is exercised through a netlike organisation. And not only do individuals circulate between its threads; they are always in a position of simultaneously undergoing and exercising this power. They are not only its inert target or consenting target; they are also elements of its articulation.

Therefore, in the contexts of negotiating who one is, power is constantly mediated and to exercise power over another can be regarded as an open strategic game, where it is possible for power to be reversed which is not necessarily evil (Foucault, 1980). The value in Foucault's orientation is that it does allow the possibility for those with less power to exercise power. Applied to living with stuttering, it means that there is potential to live differently, to take on new positions and engage in reversible strategic games to shift beyond passive, disempowering, essentialist and stereotypical constructions of PWS. Frank (2002) suggests that stories provide provisional moments of re-enchantments and researchers have the obligation to illuminate and perhaps amplify these moments. These agentic impulses are frequently debased and overlooked during narrative analysis, rendering the participant falsely helpless and passive.

In this chapter have discussed emerging issues from the personal experience research in the medically allied disciplines, issues of identity formation, and social action. The discussion has highlighted the need to bring body/impairment, Self, and society into dialogue in considering how and why participants form self-identities, and choose to act as they live with stuttering in their lifeworlds. The theory on identity

formation provides a theoretical orientation of how the understanding of identity formations is approached in this study. The understanding of self-identity formations as fluid, multiple, in process, intersectional, social and embodied, has been explained.

CHAPTER THREE

SITUATING LIFE HISTORY RESEARCH METHODOLOGY

In this chapter I shift emphasis to narrative ways of knowing, a *methodological* emphasis. I explain why narrative life history research methodology is suited to addressing the critical questions raised in this study and then proceed to discuss and problematise relevant issues. I retain a theoretical discussion on methodology in this chapter and present the practical aspects of the methodology in Chapter Four.

3.1 Introducing life history methodology

I restate here that my interest is in theorising life world experiences of stuttering over time. I admit *experience as data*. In the words of Clandinin & Connelly (1994) *stories are the closest we come to understanding experience*. We are story-telling beings and therefore narrative is a fruitful effort to “approach the understanding of lives in context rather than through a prefigured and narrowing lens” (Josselson, 1995: 32). Hence my choice of a life history narrative methodology. Although the relationships between life history and narrative methodologies are debatable, I situate life history methodology as a specific instance of narrative methodology, within the ambit of qualitative research (Hatch & Wisniewski, 1995).

Life history research as an exploratory research approach also gained momentum in the 1980s in fields of psychology, anthropology, sociology and education (Plummer, 2001). The initial impetus for life history research began in the 1920s at the Chicago School of Sociology. Plagued by a myriad of problems around practical and methodological difficulties, the method fell into disuse. It regained popularity in feminist studies that challenged the traditional authoritarian methodologies characterised in a patriarchal and capitalist society (Cole & Knowles, 2001). The voices of previously marginalised individuals gained entry through life history research. It has since become popular in many disciplines where there has been recognition of marginalised voices, where the need to understand the human perspective is considered important and valid (Denzin & Lincoln, 1994), and where there has been acknowledgement that human beings do not belong to disciplines, thereby forcing an interdisciplinary emphasis. Coles & Knowles (2001) and Plummer

(2001) provide an extensive review of life history across disciplines, which I do not repeat here.

Narrative methodology (including life history) and medical professions may seem strange bedfellows given Medicines' strong alliance with positivism. However, they share close historical connections and a resonance with respect to their goals, beliefs and methods (Charon, 2000). Firstly, literature and medicine rely on "text", (most often language-based) in order to unearth complex understandings. Importantly, the meaning is derived from more than the sum of individual words. Secondly, literature and medicine share a concern for an individual's origins and destiny. At a philosophical level they engage with questions of "Where am I from?" and "Where am I going to" (Charon, 2000: 24) with those who suffer. Thirdly, medicine borrows from literature the method of interpretive practice which requires an active reading of and writing of the life of a patient. Fourthly, they have an acknowledged reciprocity and confluence. Literature draws on medicine's plots whilst medicine respects the diagnosis and therapeutic power of words. The sensibility of narrative research is therefore clear.

Life history research must also be differentiated from other types of biographical inquiry. Life history is interested in gaining a first-hand, retrospective, historical account of the individual's personal experience elicited via the interview (Reddy, 2000, Smith, 1994) and supplemented with written and other expressive forms the participant chooses to admit. It is clearly distinguished from autobiographical writings which are self-initiated and drawn from the participant's privileged perspective (Cole & Knowles, 2001). Life history is biographical. It involves another person writing one's life via interviews with relevant people and through documents. A distinction between case history and life history is of relevance here. A case history is typically a clinical tool used primarily in the social and health services as a means of tracing the history of a disorder. A life history in contrast is a research tool which traces the life experience of a person who has a disorder or impairment (Sacks, 1985).

Although a life history may be complete, topical (emphasis on a specific aspect e.g. stuttering) or edited, it contains the central features of the individual's telling of his life, its social and cultural dimensions, and the sequences of events over time. A topical, complete (full life course) approach is used here. Sparkes (1995) differentiates between the life story and life history. While the life story provides interpretive accounts of lived experiences, it tends to exclude the social structures

and processes which have shaped that account and has the danger of romanticising the subjective reality. Life history expands the life story, and through a collaborative process between the participants, seeks to contextualise the story in a broader sociopolitical, historical and economic landscape. In drawing on the biographical, historical and contextual/ situational strands, people are not divorced from their history and context, thus laying the groundwork for agency. The data produced relies heavily on the relationship between the storyteller and the researcher throughout the research process.

Historically, life history research has featured within a realist tradition (Plummer, 2001). The shifts in the research terrain in an era of paradigmatic proliferations (Lather, 1991, 2000), require that life history research be problematised. The postmodern and post-structural positions which have made a significant challenge to the claims of grand truths and master narratives (Lather, 1991) have threatened the very humanist foundation on which life history research is based. The very existence of the human subject is contested in the work of Foucault (Plummer, 2001) and the rise of postmodernism/poststructural theory has promoted an understanding of the world as provisional, local, multiple, and in a state of flux (Denzin, 1997; Lather, 1991).

How can the life history project be understood in the midst of these tensions? There is no one resolution and the researcher must take a stance (Denzin, 1997), a side, and make choices. I feel that the postmodern/poststructural tradition offers a valuable space for researchers to work in and that life history research can benefit from postmodern/poststructural influences as some researchers have reported (Blumenthal, 1999; Cary, 1999; Dhunpath, 2002; Pillay, 2001; Samuel, 1998). However, I am equally cautious of falling into the trap of restricting this knowledge-making effort into a particular paradigm, and yet another box. Paradigms are linear structures to represent the complex nature of research (Denzin & Lincoln, 1998). The unstable oppositions and fluidity between and within the categories and paradigms are not adequately captured, and historic discussions may also give the impression of successor regimes, in which one paradigm succeeds another. For example, postmodernism succeeds realism/modernism.

Lather (2000) uses the notion of "colouring epistemologies" to make sense of the multiple knowledges vying for legitimacy and talks of the discursive, persistent and ongoing possibilities of knowledge construction. Therefore it becomes possible to

embrace multiple assumptions and to simultaneously challenge or problematise them. Research practice reflects an “irreducible heterogeneity” (Lather, 2000). I wish to view the current ferment in the social sciences methodology debate as an enriching process that can lead to new possibilities in constructing knowledge. These debates raise awareness that the assumptions and paradigms we create, are social creations. While hoping that neat paradigmatic descriptions would allow for research to be cleanly positioned, I have also discovered that the process is much less tidy than anticipated. The world of scientific inquiry is messy and the coming together of a combination of approaches creates a scenario that is difficult to unpick. Under these circumstances Connole’s (1993: 384) recommendation is that

We arrive at the only powerful means of assessing the nature and limitations of research practice - by acquiring the capacity for knowing what we are doing, why we are doing it, how we might do it differently if we choose.

A self-reflexive stance is non-negotiable. Is there potential for reconciling a postmodern stance with traditional realist notions of life history research? What of the threat of the disappearance of the human subject within the postmodern frame? These issues have troubled Plummer (2001), who explains that the interest in life history has roots in humanism. However, it also has roots in a research tradition influenced by symbolic interactionism, which, by virtue of its interpretive centre, shares an easy alliance with postmodernism. Plummer (2001) suggests that there can be reconciliation between a humanist orientation and post/late modern sensibility within a framework of “critical humanism.” I concur with this view because it allows ambivalence and ambiguity of the human subject to be retained, and to receive meaning within a political social structure, while also retaining an approach to knowledge construction as limited and partial. In this study I make a shift away from postivism in the direction of interpretive, poststructural and critical influences without settling in any one place, but rather having “feet in many places” (Lather, 2000).

3.2 Narrative: A legitimate way of knowing

Is narrative research a legitimate way of knowing? I believe it is, but also feel obliged to explain why it is, especially for those who, like myself, may be of disciplines which view “other” methodologies with some degree of scepticism. The discussion serves to reinforce the point that narrative methodologies have strong, justifiable theoretical bases. Bruner (1986) presents narrative knowing as a *legitimate* form of reasoned

knowing, given his assertion of *narrative as a mode of thought*. He suggests that we could know the world in two ways: through the logico-scientific mode (paradigmatic cognition) and storied knowing (narrative cognition). These distinctive ways of knowing, argument and story, are irreducible to one another and have their own sets of operating criteria. While both cognitions generate valuable knowledge, paradigmatic knowledge has traditionally been regarded as trustworthy and valid. Bruner's (1986) contribution lies in extending our understanding of cognition beyond that of the singular mode, modelled on formal mathematical principles and governed by a heartless logic. By contrast, narrative cognition deals with human action and intention, provides good stories and gripping dramas and is premised upon concern for human condition (Sarbin, 1986). The narrative or story constructs two distinct yet simultaneous landscapes. The first is the landscape of action in which the constituents (agent, intention, goal, situation, instrument) are the arguments of action along the lines of a "story grammar". The second is the landscape of consciousness which illuminates what those involved with the action think, feel, know, and do not know, influencing the choices they make.

The two modes of reasoning have different understandings of causality important to understand in this study. The purpose of the argument (paradigmatic cognition) is to offer causal explanations based on the relationship between dependent and independent relationships. In contrast, causality in narrative cognition seeks to explain how certain events lead to a particular end, drawing together issues of context, time, intention and action which are far more complex than dependent and independent variables. Polkinghorne (1995) provides a commonly quoted useful example to explain causality in a narrative cognition tradition. He discusses this in the context of narrative emplotment or story as a specific instance of narrative discourse:

The king died. The prince cried.

These two sentences, viewed in isolation, may be regarded as independent happenings. When composed into a story a new relational significance is evident. The king died and the prince cried - to see the prince's crying as a response to his father's death creates a new understanding. The story or narrative emplotment provides a context for understanding and clarifies Bruner's (1990) contention that people do not make sense on an event-by-event; sentence-by-sentence basis. In narrative research the intention therefore is not to merely list events but to explain how a particular outcome was influenced by a series of events (Miles & Huberman,

1994). Witherell and Noddings (1991: 280) are convinced of the value of life stories as powerful research tool.

They provide us with a picture of real people in real situations, struggling with real problems. They banish the indifference often generated by samples, treatments and faceless subjects. They invite us to speculate on what might be changed and with what effect. And, of course, they remind us of our persistent fallibility. Most important they invite us to remember that we are in the business of teaching, learning and researching to improve the human condition.

In this study, my intention is to use narratives as a basis for understanding experiences or *"lives-as-told"* (expression) in contrast to *lives-as-lived* (what actually happens) and *lives-as-experienced* (consisting of images, sentiments and desires known to the person whose life it is) Bruner (1986). Fay (1996) cautions us about creating false dichotomies, that is, stories lived or stories told. He argues that stories are lived because human activity is inherently storied. In acting we knit together the past and the future. Stories are also told and in hindsight we can appreciate the narrative patterns that we were not aware of at the time of acting. We can therefore consider our lives enstoried and enlived and combined in the telling/meaning-making process.

The expression of story occurs through language in which words combine creatively to make meaning, therefore allowing the literary text to serve the interests of "performances" (Bruner, 1986: 24) of meaning rather than conveying the meaning itself. The key point relevant in this study is that the story is produced from the "experience-as-told" via a process of active dialogic creation. It is not ethnographic or observational research. It uses personal stories in the form of language as data.

Life history and truth

The issue of truth in life history research has been of long-standing concern for life history researchers and has been raised repeatedly by critics. Some life history researchers do not think it is necessary to engage with such a discussion, while others engage with it in the context of explaining the nature of truth that life history engages. I problematise the issue because I think it is important to understand the kind of truth one engages with in any research methodology, including life history. In

the context of life stories there are questions about whether participants tell the truth or slant the truth in their favour, whether there is a good story, bad story, valid or invalid story. To begin with, one must question the kind of truth as intended in life history research.

Life history methodology privileges *personal truth*. Reddy (2000) discusses multiple notions of truth as a means of contextualising personal truths using the notions of truth described by the Truth and Reconciliation Commission (TRC) in South Africa³. These include factual or forensic truth, personal or narrative truth, social or dialogue truth, and healing or restorative truth. Factual or forensic truth refers to the familiar legal or common notion of the "scientific" truth. This is not the truth intended in life history. In attempting to excavate personal or narrative truth the Commission listened to the stories of victims and perpetrators in an effort to gain personal and rich insights into the experiences of the participants. Personal truth is the truth told in the form of a story in which people seek to illuminate how they understood particular events in a social context. It served to introduce a human dimension to understanding multilayered realities. It is this truth with which life history research seeks to engage. In contrast, social truth in the context of the Commission emerged by way of discussion, interaction and debate through processes of interaction in communities, that is socially shared understanding of events. Healing and restorative truth requires that the "facts" be placed in the contexts of human relationships, by acknowledging the experience as important, and affording the possibility of restoring the dignity of victims or healing because the story has been heard and acknowledged.

The Personal Narrative Group (1989) has also problematised the issue of personal truth in research. In the context of personal narratives, "plural" truths, experience, history and perceptions, are combined as participants select from their memories what is true for them from their positions, their personal truths. The task of the researcher then is to explain how these truths were fashioned by considering the broader contexts and relationships contributing to establishing such truths. Personal truths are subjective, constructed in stories and therefore always artificial, variable and partial. However, this does not weaken them because statements may be

³ The TRC was tasked to gain understanding of the causes, nature and extent of human rights violations in the apartheid era for the purposes of granting amnesty, recommending reparation measures, and attempting to restore human and civil dignity to victims in the interests of national unity and reconciliation (Krog, 1998). In setting out the broad framework for the Commission's functioning, the taskforce interrogated the notion of truth. They acknowledged the complexity of the construct and four notions of truth were described.

factually wrong but psychologically “true”. Stories are always told from different perspectives at particular times and it is precisely because of their perspective-ridden character that they are valued. The reason we should value personal truths is that they are generated from real positions in the world and embed passions, desires, ideas, and conceptual systems which are part of a story (Josselson, 1995). In this study I value the personal truths of participants. My purpose therefore was to create the conditions in which personal experience received illumination not with the intention to contest such truths, but rather to gain an understanding of how and why they came about.

3.3 Life history research: A suitable methodology for exploring self-identity formation

In this study I am interested in exploring self-identity formations of participants who stutter (individual subjectivities), in a social context, over time, that is, the drawing together of the personal, social and temporal dimensions of experience in a single life. Life history research is suitable because it allows engagement with all of these dimensions, the personal, social and temporal.

Life history research foregrounds *individual subjectivities* in the process of knowledge construction. It is methodology that is biographical, person-centred, and a science of the singular (in society) which seeks to understand the particular and illuminate diversity rather than suppress variability. Life history is always concerned with the history of a single life and is designed to “explain, describe and reflect upon life” (Linda Tillman-Rogers in Hatch & Wisniewski, 1995: 115). Since it is characterised by a focus on the individual, the data are produced with the participants themselves. Within the context of individual lives, life history has particular appeal as Sparkes in Hatch and Wisniewski, 1995: 116, explains:

... the ability of life history to focus upon central moments, critical incidents, or fateful moments that revolve around indecision, confusion, contradictions, and ironies, gives a greater sense of process to a life and gives a more ambiguous, complex, and chaotic view of reality. It also presents more “rounded” and believable characters than the “flat”, seemingly irrational, and linear characters from other forms of qualitative inquiry”

The individual subjective account is celebrated as a singular strength because it allows each to speak his own truth. Life history creates a space for the researcher to suspend his own views and beliefs. This is not done to agree necessarily with the participant but to empathise with the worldview and beliefs of reality that are constructed by the individual. It illuminates how s/he views the world, interprets experiences and attaches meaning to such experiences (Armstrong, 1987).

In the context of exploring identity formations, Sacks (1985: 105 -106) explains that it is through life stories that people make sense of who they are, create their identities and act accordingly.

"It might be said that each of us constructs and lives "a narrative" ...this narrative is our identities... If we wish to know about a man, we ask what is his story, his real innermost story? - for each of us *is* a biography, a story. Each of us is a singular narrative which is constructed, continually, unconsciously by, through and in us - through our perceptions, feelings, our thoughts, our actions; not least our discourse, our spoken narrations. Biologically and physiologically we are not different from each other; historically, as narratives, each of us is unique. (Sacks, 1985: 105 -106)

In agreement with Sacks, other narrative theorists (Bruner, 1990; Lucius-Hoene and Depperman, 2000; McAdams, 1993; Shiffrin, 1996) explain that first-person stories spawn a narrative identity revealing people's claims about who they are, and how they prefer to be understood by others. The story created in the context of the narrative interview is not a total or complete one revealing the totality of the individual's narrative identity. It is an identity created in the context of the research interview that is characterised by selectivity and guided by the intentions of the story (Lucius-Hoene & Depperman, 2000). The process entails a comprehensive account of the fashioning of narrative identities, which is far more intensive than a short-range account of one's experience or a casual conversation about a particular episode. Therefore, life history research is a suitable methodology for generating an empiricised narrative identity.

Life history methodology illuminates the changing nature of experiences and identity formations over time and is therefore suited to this study. In accessing understanding of experience over a lifespan, it provides a critical *temporal dimension* to understanding lives and engages an understanding of variability of identity

formations. The retrospective, longitudinal approach provides an orientation which allows the life cycle of a single individual be taken as a unit for study. There is an appreciation that with the perishing of each moment the individual is left a different creature, never to repeat itself exactly. No moment or epoch is typical of the whole (Hatch & Wisniewski, 1995).

The emphasis on the *social context* of experience is valuable. "Context is everything" (Cole & Knowles 2001: 22). Life history accesses self-referential stories, a unique point of view of the individual situated in culture, time and place. Lawrence-Lightfoot & Hoffman-Davis (1997: 41) have a useful explanation for context:

By context I mean the setting - the physical, geographic, temporal, historical, cultural, aesthetic - within which the action takes place. The context becomes the framework, the reference point, the map, the ecological sphere; it is used to place people and action in time and space as a resource for understanding what they do.

Life history is distinguished from other forms of narrative research because of its situatedness and connection to social circumstances (Hatch and Wisniewski, 1995). It therefore goes beyond a personal account. The focus on the individual allows for a deeper understanding of the complex relationships between ideology and culture, the self and society. The human experience is relational and is shaped by (and shapes) the institutional and structural organisation of society. A question often raised by life history researchers is, "do participants embed their stories and interpretations within a social landscape?" Goodson (1995) suggests that they might or might not locate their experiences in a social context. To prevent a macro-blindness, it is imperative that the researcher is an active participant in the process to broaden the concern of personal truth and to consider the wider sociohistorical concerns even if this is does not appear as part of the consciousness of the individual (Goodson, 1992; Thompson, 1981). In illuminating the sociopolitical and historical contexts, there lies the possibility that participants will gain an understanding of their experiences within a sociological context, by appreciating the forces shaping their lives and possibly leading to changes in how they understand their experiences.

Life history research has been used as means of understanding human action from a subjective perspective, that is, by linking identity formations and action. By placing the individual as active within a story, can explain why he acted in a particular way.

Personal agency of participants is encouraged rather than a passive role (Dhunpath, 2000). It is, therefore, by nature, a positive, celebratory methodology that affords a discursive space for creating and celebrating self-understanding. It allows the researcher to gaze afresh, perhaps in astonishment, at a part of the world he/she thought had already seen and understood (Dhunpath, 2002).

3.4 Producing narrative data through dialogue

Having introduced life history methodology in a general way, I now discuss what it means to produce data through narrative. The critical point about life history data is that it is *produced* in the context of the interview. The stories are not predetermined or available to be “gathered”. *The story unfolds in the context of the research interview.* The researcher features as an active and influential agent in the production process (Gough, 2001). There is no one way of producing data in narrative life history methodology. Here I draw on the work of Bakhtin (1981,1984) who has theorised the process of producing narrative data: “*I cannot manage without another, I cannot become myself without another; I must find myself in another by finding another in myself*” (Bakhtin, 1984:287)

Narrative researchers and participants produce data through *interaction*. Bakhtin's influence is theoretically appealing and useful for exploring intersubjective meaning-making. Stories as a means of accessing subjective experience are never “just there” and “ready-made”, but are constructed via dialogic processes through which the researcher and participant create meaning. The construction is therefore *intersubjective*. In this respect we cannot just get a good story but rather “invite” participation with a view to creating dialogue intersubjectively (Chase, 1995) What does it mean to be intersubjective? Gadow (1990) explains that seeing from the others' perspective constitutes the essence of subjectivity for two reasons. Firstly, the research participant is constituted as subject rather than object, and therefore *has* a perspective. Secondly, it requires engagement with the participant and demands that the researcher be subjectively rather than objectively situated, to be an actual individual, rather than an anonymous investigator.

The meaning-making process is interactive and dialogic. Meanings and words flow and influence each other and in this way participants *jointly construct meaning*. The process is one that produces *language as data* for the purposes of constructing interpretive meaning. Central to Bakhtin's thesis is that human consciousness does

not occur in a sealed internal vacuum but rather *through social interaction*. In this regard, meaning-making is always *in process*, involving the primacy of speech and consciousness and suggesting that language involves "somebody talking to somebody". The other is always present as each construction continues from the one before, leading to mutual construction. While Bakhtin's notion of personal autonomy prohibits the merger of Self and Other, it insists on mutual intersubjectivity created moment-by-moment in a non-systematic, fluid way.

Meaning-making ideally occurs in a climate that is necessarily *non-judgemental and open to possibilities* for exploration, unconstrained by hierarchies. Communicating is the key to the process of human becoming: "To *be* means to *communicate*" (1984: 287). Bakhtin's view of dialogue resonates with the views of many postmodern theorists who suggest that human behaviour can be understood through the use humans make of language, that is, through the "linguaging" of experience. Human utterances are always in relation and open to possibility. Such interaction goes beyond give-and-take, story-listening and story-telling, to a mutual interaction in which the speaker, utterance and hearer are in unfixed relations to each other. Bakhtin (1984) carries this idea a step further by suggesting that because communication/interactive possibilities occur at many levels, a good story need not include words. The "linguaging" of experience must go beyond words to include facial expression, touch, posture and all else that creates meaning.

The dialogic relationship is mutually-educative, and while it assists with discovery, it also *activates potentials*. Because nothing in the interaction remains fixed, unchallenged, or is without reconsideration, there is always a space for creating new potential and possibility. "An independent, active, responsible discourse is *the* fundamental indicator of an ethical, legal and political human being" Bakhtin (1981: 349). Narratives are externalised, multi-voiced performances that originate from the narrator's internalisation of past and imagined dialogues and encounters with the social world. Therefore, the narrative becomes a site for the analysis of the mutual constitutions of Self and social world, of meanings at a personal and cultural level. This perspective is useful because it transcends the personal/social dualisms that have plagued social sciences, not by fusing the two, but by suggesting that they are mutually-constitutive and dialogic in nature. When people construct narratives their utterances contain two voices, the voice of the speaking person and the voice of the social languages (words and voices of others) through which experience is ventriloquated. Words are socially charged, engage dialogically with past, present

and future audiences and are populated by the intentions of the peerless speaker (Bakhtin, 1981).

The task of creating dialogue for the purposes of research is not an easy one (Chase, 1995, Bowers & Moore, 1997). Chase (1995) makes an important point that researchers using interview as a method to produce data frequently invite reports instead of stories. The difference between story and report lies in who takes responsibility for the import of talk. Therefore, if we seriously want to invite stories, it becomes necessary to shift the responsibility to the participant in a manner in which he willingly embraces it, because the researcher wants to hear his story via a respectful invitation. The onus therefore lies with the researcher to be skilled in multiple ways, to ask the questions in a way that creates fertile terrain for the story to be shared. In addition to choosing questions carefully and structuring them suitably, the researcher must also deal with contradictions. For example, a participant may tell of the same experience as good and bad.

The challenge is for the researcher to create and sustain the discursive space to allow multiple realities to unfold and therefore may involve listening to simultaneous and multiple stories and self-identity formations. It is not to view the participant with suspicion when a straightforward, neat story is not available. The task of the researcher is to make sense of complexity and multiplicity in the interests of knowledge production. As already stated, in dialogic interviews, identities are made through the conversation. They are not pre-given external identities. The process could be regarded as "identities in the making" in a unique interaction between the researcher and participants (Lucius-Hoene & Depperman, 2000). The active creation of narrative identities requires that the storyteller/participant steps back from everyday life episodes to reflect on his life, and events and episodes which have shaped him in an act of self-creation. In doing this he has the task of revisiting and engaging with his life as a whole drawing on his personal stock of experiences, always influenced by the researcher, by her orientation, questions and responses (Lewis, 2001).

In creating his self-identity the participant positions himself in multiple ways temporally and across situations, explaining how particular identities came to be, or were disrupted (Lucius-Hoene & Depperman, 2000). He may explain how his former self came to be, why he acted in particular ways and reflected on these actions. By telling his story from multiple positions, he may reveal the tensions between identity

formations, or how particular identities were strengthened. In the process of the telling he may also position the researcher differently, for example, as a mother who could understand what it must be like to have a child with a problem or as clinician. The narrative identity therefore has its social origin in the research context and can be regarded as an *in situ performance* of identities and challenges the researcher to listen also to unexpected stories (Cary, 1999).

3.5 Problematising methodological concerns

3.5.1 Life history research, relationships and positionality

Life history research is premised on a good relationship between the researcher and participants given that meaning-making is dialogic. It is through this relationship that the data is produced and analysed. Therefore, the nature of the relationship must be problematised. The social nature of the process could be said to occur on a continuum. The one end is formal and distant to allow the researcher to maintain her objectivity and necessary rigour. On the other end, the researcher sees it necessary to develop a reciprocal relationship that affords the opportunity for deeper engagement (Lawrence-Lightfoot & Hoffman-Davis, 1997). Researchers are somewhere on this continuum.

In fostering a reciprocal relationship in life history research, it is also important to consider how researchers and participants are positioned. Who is the participant I want to study? A person who stutters who is different/Other to me? A person who occupies a single position as one with pathology and disability? Is he a creator of his own future? How do I construct Myself - as opposite to him? As a fluent speaker (who also has some speech disfluencies), as a person without disability (yet who feels disabled at times)? bell hooks (1989) describes this issue as the politics of location, or as Lather (1992) says the politics of positionality. Within a postmodern discourse, narratives celebrate and promote the possibility of eroding fixed categories and reconfiguring the boundaries between researcher and participant as Self/Other. Working-in-Hyphens (Fine, 1998) is a sensible approach to unravelling this difficult problem. Fine (1998: 135) suggests that when working with participants we are always in multiple and improvised relationships in an effort to improve the quality of data. Working-in-hyphens means:

creating occasions for researchers and informants to discuss what is, and what is not, 'happening between', within the negotiated relations of whose story is being told, why, with what interpretation, and whose story is being shadowed, why, for whom and with what consequence"

At the same time however, what is understood at the poles is equally critical.

The knowledge production process interested in understanding the archetronics of Self through dialogue, must be premised on empathy. It is only by appreciating closely and intimately the dynamics between the interplays of the selves and the dialogue of selves with the world, the researcher can construct a story of the "whole". It is through recognition of the interplay of the various parts that a story can be written and the researcher is in a position to "imagine the real" (Josselson, 1995: 42). Josselson (1995) is emphatic that we listen to all dimensions of the very personal, moral and social to do justice to the "whole" person in a way which embraces the essential message of a hermeneutic research stance, in which "to be human is to mean". She therefore regards the telling of life story as a very sensible way to understand multifaceted human realities.

3.5.2 Not innocent: Ethics & Politics

Whilst dialogic engagement is necessary, the research process is not an innocent process. A story is always told with someone for a particular purpose. Who decides what story is told and for what purpose? The interests of the researcher in particular must be understood. What does the researcher attend to, and why? The research relationship therefore must be problematised, especially because academic scholars schooled in positivist traditions may be destabilised during narrative research. They must suspend aspects of their academic training to fully appreciate participants' stories (Casey, 1995). An emic approach (Quantz, 1992) to the knowledge construction project requires that the researcher limits the urge to apply an external and restrictive structure to the interview. The interpretive process must be flexible enough to follow the lead of the participants without losing sight of the object.

As I have already said, narrative researchers in the medical field engage participants in the telling of life experiences from a singular positioning of participant as patient. This has allowed reductionistic, essentialised, passive medical narratives to emerge. It is only through reconfiguring the positionality between researcher and researched,

and working with participants for the purposes of constructing knowledge, that we can hope to produce knowledge which works against subordination and subalternity (Spivak, 1988). In a dialogic process, the researcher cannot roam silently and imperially in the research process. This would threaten the very intention to admit subjectivity by separating the researcher/observer from the researched, creating a dualism that the methodology seeks to obliterate. The mismanagement of power can endanger the very intention of co-construction and therefore must be attended to as a core concern in the process.

The researcher is likely to commit symbolic violence (Bourdieu, 1999) when she constructs herself as an “imperial I” and participants as a homogenous mass of oppressed, disabled people. The issues of importance to participants may be masked and there may only be extractions of what she wants to or only can hear, in turn convincing some participants that what matters to them is inferior or not important. Although participants have actively participated in producing knowledge, there is always the risk that the knowledge can work against them, creating further subjugation in what appears to be a democratic participatory process. While we may never be able to eliminate power imbalances, an awareness and steps to minimise its potential threat are essential if we seek knowledge that is interpretative and co-constructed.

In most research projects subjects may be described in detail, but the researcher remains anonymous. How much of who the researcher is should be declared? Does the researcher become the focus of the study? In this study I feel it is necessary to understand my role in actively creating meaning. I therefore have declared my concerns, interests, and theoretical positioning. However, at the same time, I do not wish to mask the issues emerging in the stories as these remain a primary emphasis.

3.5.3 Problematising narrative research methodology with PWS

Against the background of the dialogic creation of narrative identities and issues of ethics and power, I must problematise the use of life history methodology with participants who stutter. In this study I am accessing stories of people who have traditionally been constructed as having communication problems (as defined in the profession). This may appear as an anomaly – a contradiction. Can someone who has a communication disorder tell his story? Is it possible that I would further threaten his sense of power by asking him to be part of a process which privileges speaking

as a means of meaning-making? These possibilities exist, but I present a counter position. People who stutter can tell stories and do tell stories. I have heard many stories as a clinician and from PWS in various settings. Creating meaningful communication is the first and fundamental step in restoring humanity, something we have not been successful in doing especially in the research arena because we have constructed the participant as object, passive or subaltern.

Is the PWS subaltern? Can the subaltern speak? As a first step, let's consider who is "subaltern" According to Spivak (1988), it is not just a classy word for oppressed, Other or for someone who is not getting a piece of the pie. It refers to those whose voices have been written out of the capitalist bourgeois narrative, or in post-colonial terms everything that has limited access to cultural imperialism is subaltern. Given the dominant research tradition within the profession I argue that PWS have been constituted as subaltern because their voices have been excluded in research. Their participation thus far cannot be described as equitable. This study intends to install greater equity in the research process by engaging the voices of PWS.

Can the subaltern speak? Yes. The people on the margins, and PWS, can speak and have spoken, outside of the research domain. They do have stories to tell but the mechanisms for appropriation of these voices do not exist in a dominant research tradition. PWS can speak and do speak. They speak with a stutter. Some may have great difficulty with the flow of speech but are able to communicate. The problem is that they have not had an ear within the research arena. There has been no listener and no dialogue to develop communication and meaning. Engaging in the dialogue does not mean that the researcher speaks for the participants or offers participants a voice. Spivak (1988) is adamant that no researcher who works in the interests of her participants speaks on behalf of them or gives them voice.

The researcher must translate such ideology into practice. Once again Spivak's (1995) advice is useful. She suggests that the researcher should recognise that her privilege is also a kind of insularity that cuts off privilege from certain kinds of other knowledge. One should therefore strive to recognise these limitations and overcome them not as a magnanimous gesture of inclusion, but simply for the increase of knowledge. The way to do this is to work critically through one's own beliefs, prejudices and assumptions, understanding how they arose and became naturalised. At a practical level it means interrogating who I was, who I am, where my own knowledge base comes from, what my concerns are, (as I have presented in Chapter

One) and continue to share throughout this process. The researcher undergoes an obligatory process of self-discovery (Plummer, 2001), as she interrogates herself as the instrument. I have attempted to suspend my own judgements to allow for understanding another point of view.

The potentially disruptive influences of the stutter must also be problematised. Would the stutter not influence, impede or limit the research process? What if the participant had difficulty speaking or I listening? This was a challenge I had to entertain. I did so by considering each case individually because of the great variations among PWS. I took an exploratory-learning stance in the research process, which I detail in the next chapter. However, the most important guiding principle was that I was not interested in their speech *per se*. I was interested in hearing their stories. I had to shift focus and learn how to listen to the story, with the stutter.

It could also be argued that by exploring experiences of stuttering I was forcing participants to occupy a particular position in the interview and to create another stereotypical identity. I was still exploring the story through the lens of pathology. This is so, and perhaps not unexpected, because the need for this research arose from my clinical concerns. However, I am prepared to listen to and encourage a different story from the stereotypical one. I was interested in their constructions of themselves from multiple positions in a social context. Therefore it was necessary for me to remain vigilant about whether or not I was forcing a fixed and negative orientation given my professional socialisation, or creating a space to hear the participants' stories.

3.5.4 Memory and life history research

The participant is engaged with the process of recounting his experiences over time. This process relies on memory and the issue must therefore be considered (Thomson, Frisch & Hamilton, 1994). The concerns which surface include the reliability of memory, the extent to which memory is factually accurate and the potential distortions of memory. How will this impact on the research interest? The use of memory as evidence has been challenged by traditional historians who seek factual truths. However, the purpose of life history research is different from historical research. It is not intended to generate factual truth, but to generate personal truths. Therefore, memory must be understood differently.

Life history research is an active process of recollecting, rediscovering and creating. Memories may be said to be working at many different, interconnected levels (Plummer, 2001). Firstly, at the personal psychological level one considers how well and what a person can remember given his individual constraints such as time of day or diseases affecting memory. Secondly, memory in narrative research has been understood as more of a socially shared experience than an inner psychological phenomenon. Memories are our habitual stories about what we have come to believe is true, and in this regard, can be considered as a narrative memory. Bruner (1994) explains that what we remember of the past is what is necessary to keep a story well-formed. A third level of narrative memory is a collective memory where the emphasis is on the social framework of memory. Life stories are narrated within a broader cultural frame. Story-tellers rely on the collective memories of events passed on through generations and include in their stories aspects of cultural heritages. They are able to relate events which they have not directly experienced but which have become part of their “vicarious” experience through stories told by others, for example, atrocities during war times or living in apartheid times. Memories of living conditions, experiences of families and critical events may become part of an individual’s experience as stories are passed down through generations. Memory can therefore be constructed as an active, personal/social process of linking the past to present, which has relevance for the construction of a particular story.

Memories serve to construct identities. In creating ourselves we always rely on our memories (Bruner, 1994). Without such memory how would we know who we are? It is a process that extends from childhood to adulthood and is under constant revision. The Self is always a remembered self. Tutu (2001: vii) points to the importance of memory in the context of identity formations in a changing world:

And what happens if I lose my memory and forget who I am or to whom I am related? My identity is very intimately linked to my memory, and relationships would be impossible if memory went - that is why Alzheimer’s disease is such a horribly distressing ailment. ... Without memory it would be impossible to learn: we could not learn from experience because experience is always something remembered. ...What I know is what I remember and that helps to make me who I am.

In the context of research one must then ask the difficult question about whether it is plausible to rely on individual memory as a basis for theorising. If one is interested in

personal experience, then it is the interpretations of those memories that must serve as evidence. It may be irrelevant whether or not a participant can remember the exact date and time of a life event, but it is important that he can place it within a meaningful temporal context. In the interview, the researcher may want to check for internal consistency by revisiting aspects of the experience and comparing with other sources, if necessary and possible.

The challenge for the narrative researcher therefore lies in appraising the particular kinds of questions she asks, and the ways in which she asks these “watershed” questions. These questions unlock a stream of memories that may be considered extraneous to the researcher’s objective but also create the possibility of illuminating unanticipated rich data (Barone, 2001). However, the unlocking of such memories is also built on a solid bridge of interpersonal trust, respect and dignity (Antoinette, 2000). As a counterpoint, Dhunpath (2002) suggests that we should also ask what about the silences - about what is not said or not remembered. It is unlikely that we will know with any degree of certainty whether silence on particular issues are a conscious or unconscious act and the extent of self-censorship or strategic selection an individual is likely to make. The dilemma is a difficult one for the life-history researcher and perhaps it can only be approached with an attitude of sensitive caution to what the participant wants or chooses to make public. What is said, what is not said, what can or can’t be remembered, are part of the story. It is a difficult path the researcher must negotiate. It is here that the ethics and politics of the research process become paramount.

In this chapter on life history research methodology I have explained why life history is suitable for a study of this nature and problematised the issues of memory and power, and the application of the methodology with PWS. The practical aspects are described in Chapter Four.

CHAPTER FOUR

METHODOLOGY: ISSUES AND CHOICES

In this chapter I discuss the issues and choices made in translating the theoretical frame presented in Chapter Three into practical design. The issues are presented in four sections. In Section One I discuss the preparatory steps in the study, pilot study, participant selection and research instruments. In Section Two, the emphasis is on producing data in the interview process and problematisation of issues arising therein. There are three levels of analysis in this study I discuss in Section Three, explaining how they relate to one another, how data is represented and details of how the processes unfolded. I conclude the chapter with Section Four with a review of issues of quality in the research process.

Throughout the chapter there are two central stances which guide the choices I have made. The first is to adopt Reflexivity as the primary guiding stance. Reflexivity is “the capacity of any system of signification to turn back upon itself, to make itself its own object by referring to itself” (Meyerhoff & Ruby, 1992:307). I heed the advice offered by researchers who have engaged with similar qualitative methodological approaches (Ahern, 1999; Alvesson & Skoldberg, 2000; Angen, 2000; Connole, 1993; Denzin & Lincoln, 1998), who have strongly recommended that researchers become reflexive for the purposes of enhancing quality. As researchers, we are part of the social world we study, and therefore, in a project such as this one, where the researcher plays a critical role in producing data, it becomes necessary to examine and declare my embedded assumptions, values, interests, problems and choices, as well as the influences on the research process.

Closely linked with the construct of reflexivity is the “circularity” of the research process. Traditional research processes are often described as proceeding in a linear manner from theory to operationalisation and validation. In contrast, circularity in the research process requires that the researcher, by remaining reflexive, is able to reflect on the different steps of the process in the light of others and to revise and make decisions about how to proceed (Flick, 1999). Although I have presented steps in the research process sequentially, they have been constantly interacting, under revision, and have influenced my decision-making. For example, while I discuss analysis and interpretation in Section Three, the analytical process had begun with

the first interview, and continued throughout the research process as I moved back and forth between processes.

Section One: Getting Prepared

In this section, I discuss three central parts of the research process as preparatory stages of the data production: the pilot project, participant selection issues and research instruments. The pilot phase entailed a case study, which I completed from beginning to end, that is, from preparation to data analysis, including a review of quality concerns. In the discussion of the pilot phase, I present emerging issues and concerns but I do not explain the choices I made to avoid repetition. Instead, I integrate these choices into each aspect of the research process following the pilot phase. Participant selection issues and the initial contacts are discussed and followed with a summary description of participants presented in Table 2. The research instruments include discussion of the interview schedules used, and the concept of researcher-as-instrument.

4.1 Pilot Phase

As a novice researcher doing life history research, it was important to understand theory and develop my practical skills: My learning and reflection (Appendix C) began with a pilot project with a single participant. The project served the purposes of:

- ◆ Developing the theoretical frame for the application of life history research with PWS
- ◆ Learning about the methodology, namely preparatory phase issues, data production, interviewing skills and data analysis.

I began the pilot phase in search of a participant who would be prepared to accommodate me as learner in the research process. The volunteer was comfortable that this was a learning process, and agreed to discuss the aspects of the research process with me in a direct and honest way. He was a black, male, 38 years old, of Zulu cultural heritage, bilingual and employed as a community liaison officer in the local government council. We completed the interviews in four sessions, a total of seven hours. Thereafter, I experimented with the story as a representation device (presented in Appendix C), which he reviewed. I conducted a preliminary analysis

which I formalised as a journal publication (Kathard, 2001). I also presented papers at three conferences⁴, one professional and two on qualitative research methodology to obtain feedback on issues of methodology, and theory.

The pilot project and feedback from conferences drew my attention to many aspects with which I had to engage critically. I highlight only the most salient learning issues.

- ◆ Application and problematisation of life history research with people who have communication disorders.

Although interviews have been used extensively in research with PWS, the interview as a primary data production method with stuttering has not been sufficiently problematised. I was using a methodology which required speaking with people who have "speaking" difficulties. There was a need to consider how this would be managed practically in the research process, especially with participants who had a severe stutter.

- ◆ Developing listening, interviewing and interpretation skills as a fundamental aspect of data production.

Although I had been trained as a clinician and had substantial experience with clinical interviewing, life history interviews were different. It was necessary to develop skills for listening/interpreting i.e. listening to the meaning and not just words or symptoms. I realised during the initial interviews that I was listening for technical content without interpreting the story. I also realised the importance of understanding the participant's perspective by minimising the extent to which my own frame of reference was allowed to dominate. I had to understand myself, researcher-as-instrument, to be aware of how I was shaping and distorting the process by asking what I wanted to know rather than listening to the participant's story. I gained clarity around these issues during my discussions with fellow researcher and practitioner,

⁴ Professional Conferences

Kathard, H. (2002). Life histories of PWS: Talking back to the profession. Paper presented at symposium on Life History Research, Advances in Qualitative Research Conference, Sun City, 24-25 January 2002.

Kathard, H. (2001) Life history and narrative as research tools in stuttering. Paper presented at Royal College of Speech Therapists Annual Conference, Birmingham, April, 2001.

Kathard, H. (2000). Stories lives tell. Towards critical research with multicultural/multilingual populations. Paper presented at the 2nd International Symposium on Communication Disorders in Multilingual populations, July 18-21, Kwa Maritane, South Africa.

Ruth Beecham, and seminar forums during the doctoral programme. These served to sharpen my skills as a researcher.

◆ Representation issues.

I was aware that the data could be represented in many ways. During the pilot phase I experimented with different forms of representations e.g. abstracts of verbatim data, edited dialogues and vignettes, but I found the story, to be an appealing form of representation. However, there were many issues I needed to consider in writing research stories, for example, issues of voice, plots, themes, characters, writing.

◆ Participant inclusion and negotiated analysis.

Throughout the process I became aware of the issues of power relationships and potential for imbalances in the research process. It was necessary for me to problematise this issue because the methodology is a delicately balanced joint-construction activity which is inherently influenced by power dynamics.

◆ The research questions.

The research questions were difficult to frame because the research process was evolutionary. I began with wanting to know about particular dimensions of living with stuttering. However, as I listened to the story and read the literature, new questions and issues began to emerge requiring dynamic and ongoing revision of the questions as I began to understand the research process and emerging issues better. In particular, the issues of self and identity formation began to feature prominently in the pilot phase, which served to inform the critical questions in a direct way.

◆ Theory.

It had also become apparent that in choosing to understand lives in context it became necessary to explore theory outside of my professional discipline. I needed a theoretical basis for both the methodology and theoretical interests of the study, for example, issues of identity formation, disability activism, sociological constructions of

health and disability, psychological issues, among others, which I have presented in Chapter Two.

4.2 Inviting Participation

In life history research one has to choose a few participants compared to large scale survey research where there is an interest in large numbers of participants. The researcher must make choices from the many potential participants (Plummer, 2001). The sampling, to begin with, was purposive and the choices were guided by three key concerns:

- ◆ Participants who could and were willing to provide rich information as critical and sensitive case selections (Plummer, 2001).
- ◆ Those who had critical experiences around particular dimensions of experience of stuttering e.g. living successfully or specific life events (Flick, 1999).
- ◆ Diversity, because I wanted to understand experiences of participants of diverse life contexts in KwaZulu-Natal, South Africa, described as maximal variation sampling (Flick, 1999).

Although primary selection criteria were in place at the outset, the selection process unfolded gradually as the interviews proceeded. At each point in the process, different participants were selected for different reasons to achieve maximum variation across participants or because I needed further cases to understand a particular issue. This process has resonance with theoretical sampling originally described by Glaser and Strauss (1967). These sampling decisions were intended to produce data that offered insights into emerging issues. For example, having interviewed a male participant, I was interested to understand a female experience. Theoretical sampling, however, is influenced by practical matters of convenience (Patton, 1990), like who is available and willing to participate.

The primary selection criteria were:

- ◆ Adults with experience of living with stuttering

The first major concern was how I was going to ascertain who stutters and by what definition or criteria. This seems a ridiculous concern because I am a speech pathologist who can easily identify stuttering. However, given my stance on valuing subjectivity, and inherent difficulties with “objectively” assessing stuttering, I invited participants who described themselves as having a history of living with developmental stuttering (Guitar, 1998), that is, symptomatic onset of stuttering during childhood, and persisting through their life courses. This is in contrast to “acquired” stuttering as a consequence of head injury or psychological trauma later in life. Participants were required to be at least 18 years old since I was interested in experiences of participants over their life courses, including adulthood. However, because stuttering can persist into later adulthood and there is limited understanding of experiences of older adults, I invited one participant who was 65 years old. The age range of participants was between 19 - 65 years, in the interests of diversity.

- ◆ Willing informants

Participants were required to be willing informants who were able to sustain a prolonged period of engagement. They had to be willing story-telling participants. I encountered some difficulty with potential participants I invited, but who did not feel comfortable with telling stories to a stranger. I realise that life history narrative research attracts a particular type of participant who is willing to share a personal story.

- ◆ English as the language of communication

Participants were required to speak English as a language for functional communication. I am a monolingual English speaker and I felt that it was important to engage personally with participants. As a novice researcher I did not want to complicate a delicate and sensitive process by working via an interpreter.

Secondary considerations included:

◆ Severity of stuttering

I invited participants who described their stuttering on a continuum from mild to severe. It was important to gain understanding of how the differences in severity of stuttering shaped their experience. However, descriptions of severity are inherently problematic (Cooper, 1987; Guitar, 1998). Who describes severity and on what basis? In the context of this study the issue was difficult to resolve because the severity of stuttering is variable over time and context within a single life, and may be judged differently by participants and observers. I used the participant's self-rating of stuttering severity at the time of the interview. However, in the context of their experiences over time, the issue of severity receives further emphasis in the participants' narratives.

◆ Gender

In the literature it has been established that there are more males than females who stutter, with a ratio of 3:1 male to females who stutter (Guitar, 1998). In keeping with this ratio I included both males (5) and females (2). I deliberately included female participants because stuttering research is dominated by male subjects. There is little understanding of the experiences of females or the understanding of the gendered nature of stuttering experience (Silverman, 2001).

◆ Race

South Africa has a well-known history of racial segregation. I felt it would be important to engage with participants from all race backgrounds. I was successful in inviting Black, White, and Indian participants but not Coloured participants. The Coloured participants I invited were unavailable for various reasons.

◆ Exposure to formal therapy

While most research includes those who access formal help, I also wanted to include those who did not access formal help. Many PWS in South Africa and throughout the

world, do not access formal help and they have traditionally been excluded from research samples (Kehoe, 1998).

◆ Success in living with stuttering

Typically, the research studies have included those participants who have had limited success in living with stuttering. In the context of this study it was necessary to include participants who had varying degrees of success in living with stuttering, by their own definition. As the sampling process unfolded, I considered participants' appraisal about their successes in living with stuttering, as a basis for inclusion in the study. This was done in the interests of maximising diversity and understanding the experiences of those who also live successfully with stuttering.

◆ Geographical region

All participants were from urban and peri-urban regions in the province of KwaZulu-Natal, for practical convenience. Given the prolonged nature of the interviews and number of contacts necessary, I invited participants I could access easily given my time and budgetary limitations.

◆ Occupational and Educational considerations

In the interests of diversity I invited participants of varied occupational and educational backgrounds. Although it was my intention to invite people of diverse educational backgrounds, all participants, with the exception of one, was university educated. However, the specific contexts of their primary, secondary and tertiary education varied. My primary interest was in their *life* experience. It was difficult to gauge the socioeconomic circumstances of participants especially because this changed over their life courses.

Seven participants were selected to participate in the project. I invited those I knew well through my professional association with them in support groups or at the University Clinic, whilst others were accessed via referral. Table 2 presents a summary description of biographical profiles of participants.

Table 2: Biographical profiles of participants

Participant	Gender	Age	Geographical Region (current)	Race	Severity of stuttering	Therapy	Occupation/ Education
Gareth	Male	65	Durban	White	Mild	Yes	Retired architect; University educated
Hennie	Male	29	Pinetown	White	Moderate to severe	Yes	Accountant; University educated
Siyanda	Male	32	Inanda	Black	Moderate	No	Director: Arts Association; High School: Standard Nine
Thabo	Male	19	Ashdown	Black	Severe	Yes	University student. Tourism University educated
Kumari	Female	36	Shallcross	Indian	Mild	No	Accountant; University educated
Sagren	Male	32	Pinetown	Indian	Moderate	Yes	Manager/ middle class University educated
Nontokozo	Female	20	Umlazi	Black	Severe	Yes	Student middle class University educated

4.3 Initial contacts with participants

I established contact differently with each participant. Mostly, I contacted them telephonically or met personally with them and explained the nature and purpose of the study. I invited them to participate after a brief screening process to establish that they did stutter and that they had a story to tell. The format of interviews, the processes that followed the interviews, and the prolonged nature of the process were explained to each participant. Participants were allowed time to contemplate their involvement prior to providing consent. I initially invited ten potential participants. However, three participants were unavailable. Two potential participants were unavailable for logistical reasons (work schedules and not physically present in KwaZulu Natal for the duration of the research process. The third individual declined to participate because he was uncomfortable with a research process which depended on verbal communication. I therefore invited a total of seven participants. As a novice researcher with this methodology I began the interviews with those participants I knew well.

At the first interview session, participants were presented with a set of guidelines (Appendix D) and further details about the intention of the project, nature of the research process in general, and the initial interview process in particular. The days, times and venues for the initial interview were negotiated and varied for participants. In general, I tried to arrange a suitable time on a weekly basis, arranged over three to four consecutive weeks. Each interview was scheduled for 1.5. to 2 hours. The venue selected included participants' homes, local libraries or university campus facilities. It was important to use a quiet, private and comfortable venue for the purposes of audio-recording and to facilitate sharing of personal experiences. Participants were also required to confirm their voluntary participation in all aspects of the research process. A sample copy of the confirmation form is in Appendix E.

I agree with Measor and Sikes (1992) that the research process should be negotiated and that the expectations, rules and the nature of the research relationship should be discussed as a way of developing respect and fairness. The initial points raised therefore were:

- ♦ The process was interactive and was intended to understand participants' experiences of stuttering. The selections and choices were theirs and they were free to include aspects they thought relevant.

- ◆ I was not as positioned strictly as clinical practitioner in the interview, but rather a researcher interested in how stuttering was experienced in their life worlds. In this regard the process would necessarily unfold differently to the traditional case history interview participants may have been exposed to in therapeutic contexts.
- ◆ I did not intend to “assess” the stuttering disorder as is done in clinical environments. The emphasis on the actual moment of stuttering and frequency counts were not the focus of the interview. The interview was intended to understand their experience and not to detail their symptoms of stuttering.
- ◆ The conversations would be tape-recorded for the purposes of transcribing and data analysis.
- ◆ They were not obliged to share information they regarded as confidential, and needed to inform me of issues they were not comfortable talking about or preferred to talk about at another point.
- ◆ They also needed to make me aware of their general well-being during the interview, to request a break or to discontinue should they feel physically or emotionally strained.
- ◆ Participants were made aware that their identities would be protected. I contracted not to reveal the names of participants and to limit the contents of the cassettes to myself and those involved in transcription and analysis processes. Pseudonyms were used for representation purposes.
- ◆ They were invited to participate in various parts of the research process including the processes of data representation and analysis, insofar as they chose. Their feedback and comments were important and would be considered in the process of theorising.

4.4 Research Instruments

4.4.1 Interview schedules

Although the life history interview process invites participants to tell their stories, it is not without direction, given that the project addresses specific critical questions. Interview schedules were constructed with the aim of structuring the process and keeping the life history frame as a deliberate orientation.

- ◆ Temporal emphasis: the schedules were structured to trace changing life experiences from childhood to adulthood.
- ◆ Social emphasis: it had to assist with accessing experiences within a social frame, as the influence of society, family school and life circumstances were important.
- ◆ Personal Frame: participants' personal sense-making of their experiences and issues of importance to them, was critical.

The interview schedules were a supportive tool developed to give direction to the unfolding process, but not intended to constrain it. The schedules were revised after the pilot process in which I found some questions too broad and others too specific. I prepared four related schedules each with a specific purpose (Appendix F). Each schedule had a guiding initial question intended as open-ended, followed by in-depth questions. The first interview schedule was designed to trace significant life experiences and events, in general and specific to stuttering, from childhood to adulthood. The second schedule was constructed to focus on a detailed exploration of stuttering experiences in varied life contexts. The third schedule was structured to illuminate how participant's negotiated stuttering over their life courses. The fourth was designed for summarising, clarifying and selecting those experiences most critical to their stories.

4.4.2 Understanding Myself: Researcher-as-instrument

It was necessary for me to understand myself in the context of researcher-as-instrument, a termed used by Harry (1996) to highlight the need for researchers to problematise their participation in knowledge construction processes which require

their active and influential participation. In this regard, Peshkin (1988, 2001) recommends using a *well-informed subjectivity* to reveal the multiple personas of the researcher. It became necessary to reflect on my own background, assumptions and positioning throughout the process. I was certainly present, had ideas and spoke from different positions. As a researcher in the process, I could occupy a variety of positions including female, mother, daughter, wife, Indian, university student and advocate, not just a single position as clinical practitioner or educator. My different subjectivities admitted a range of interests, beliefs and questions for me as researcher. In a similar fashion, the multiple subjectivities of participants are also admitted.

The interview therefore was intended to create a space for discursive engagement from multiple positions. Positioning was not regarded as bias and it was not possible to eliminate it. Truth is constructed in the midst of these influences (Chesney, 2001) which place knowledge construction as a state of flux. I was also aware of my positioning and careful not to impose judgements and decide what was right and wrong, for example, when participants told me about why they made particular choices. I wanted to make meaning, to understand their experience, not judge it or their actions. I positioned and repositioned myself, probed and discussed issues in detail with the specific intention of gaining a perspective on how they understood and acted in different situations. I was therefore not passive in the process but actively creating meaning with participants.

It was necessary for me to learn to tolerate and embrace uncertainty in the interview process. This was different to my prior experience of interviewing which entailed structuring and directing the interview process. Life history interviews unfold in a fluid way, and I was often not in control compared to when one administers a questionnaire. Therefore, I had to learn to tolerate and appreciate uncertainty of the unfolding process as positive learning and to allow the interview to run freely except if the topic was definitely irrelevant to the focus of the research. There were points at which participants raised issues I could not appreciate because of my limited exposure to such matters. In these instances I continued the conversation with the intention to learn about the issues through the participants. On several occasions, I read relevant material or explored particular issues in greater depth at a later stage of the interview.

Section Two: Producing Data

In this section I present a detailed overview of the interview process which served as the primary data production method. The production of data using an interview as method demands a review of critical issues, namely empathy, trust and power, which influence the process. The specific interviewing strategies, issues of sensing and connecting, are explained. I conclude this section with a discussion of memo-writing during the research process.

4.5 The Interview Process

The interview as the primary method of data production was scheduled over a two-month period for each participant. They were organised sequentially and did not overlap between participants because I needed to afford optimal time with each participant to engage intimately with each story. Also, structuring the process in this way provided the opportunity for considering the guidelines for selection of successive participants. In retrospect, I felt that this structure was beneficial because I had sharpened my interviewing skills over time, and I was able to gain clarity of emerging issues across participants. The initial data was produced over a twelve-month period during 2000 - 2001. The details of scheduling are presented in Appendix G.

4.5.1 Developing the research relationship

There are varying types of relationships between participants and researchers ranging from formal to intimate (Plummer, 2001). The relationship I aimed to develop could be described as a friendly partnership in which the researcher and participants were conversational partners. There was a need for us to get to know each other better through creating a common/shared discourse around the focus of the interview. The first challenge was therefore to become acquainted. We shared many commonalities but we were also of different backgrounds. Therefore, there is also a need for "bridging the gap" (Rubin & Rubin, 1995) for the purposes of developing the research relationship as these impact directly on the production of data. In my view the "distances" such as age, gender, cultural backgrounds between us did not make the conversation difficult, as one might expect, but served to make the discussion more informative. These "barriers" provided opportunities rather than obstacles because the process unravelled as one of discovery. I knew some participants well

prior to the interview but our relationship needed to be developed further in the context of the research process. However, with those I didn't know, it was necessary to spend a brief period sharing our respective backgrounds and getting acquainted.

It was necessary to foster a research relationship that would be mutual, trusting and empathetic because the construction of authentic knowledge comes only through the construction of authentic relationships (Lawrence-Lightfoot & Hoffman-Davis, 1997). While the notion of authenticity is contestable, one must consider what kind of relationship is optimal in a study which is interested in personal truths. The process therefore depends on a relationship between participants and the researcher that is conducive to such personal meaning-making. Issues of warmth, empathy, trust, respect, genuineness are core to the research process (Josselson, 1995).

I recognise that "we never meet each other naked", as complete strangers. However, *a priori* assumptions can be dangerous. At the outset, therefore, we clarified assumptions we each held about the purpose of the interview, to ascertain how we saw each other in this context. One participant said he was pleasantly surprised to discover I was not an "old professor" as he had anticipated. I agreed to conduct the interview in his community, which he regarded as a sign of respect. Some participants said that they were intimidated initially because I was unfamiliar, and a lecturer. However, having experienced the casual tone of the interview, they reported being more comfortable and interacted more freely. Although I felt closer to some participants than to others, in general I felt we had a healthy, friendly, respectful relationship conducive to data collection.

I found that after the purpose of the interview was clarified, the participants appeared comfortable with the types of issues raised, and the discussion became more focussed. We adjusted to the communicative styles of each other and the conversations flowed easily. However, it became necessary to negotiate how to handle particular issues as they arose. For example, with a participant who used English as a second language, we negotiated what was necessary to achieve meaningful communication. One participant suggested that it was useful to help him "fill in words" when he experienced difficulties selecting suitable English words and that I should use simple, everyday language rather than "high academic language". Ordinarily I would not have "filled in words", but his direct request proved to be useful strategy although I needed to use it only occasionally. As the process unfolded he became aware that I was not expecting "academic" language. Another strategy

participants used was expression in their vernacular. I asked them to elaborate and explain these to me.

Two participants stuttered severely and I had to negotiate with them about how to manage the communication. I explained that the situation was difficult for me because I could not pretend that the stutter was not present or potentially disruptive. There were times when the stutter was so severe that I didn't understand what they said and asked for repetition. At times they answered questions with single words or short answers as a means of containing the fluency disruptions. At points the interview began to slide into a question-answer format and I seemed to be directing the conversation too much. I addressed these issues with the participants when I felt that we had become sufficiently acquainted.

I reinforced my view that I was interested in listening to their stories. My asking them to repeat or clarify what they had said was not a sign of not listening or disrespect. I did this because I wanted to engage with them. I also made clear that I was not judging them on the basis of their stutter. Participants made various suggestions to guide me in this regard. Some suggested that I wait until they had completed speaking, and not to fill in words or guess when they were in a block. Some suggested that although eye contact was necessary, they were not comfortable if I "stared" at them while they were in a block. We considered options of writing as a supportive option, but none of the participants felt that this was their preferred option for various reasons. Two participants who stuttered severely provided written notes about their experiences in lieu of the interview as a means of supplementing what they said.

The relationship evolved over time. During the initial stages the potential of power imbalances was more apparent. Although I had set the agenda for the research and the framework for the discussion, participants were encouraged to steer the interview in selecting to speak about issues important to them with intention to admit stories. I intervened only if the discussion had steered too far from the scope of the research. However, if participants felt the issues were important to raise and wanted to continue, the opportunity to do so was available. As power shifted in the research process, the participants and myself became flexible and comfortable from our respective positions allowing for an in-depth exploration of issues benefiting the process (Lincoln in Ebbs 1996). I also explored sensitive or controversial issues,

such as disclosure or traumatic relationships, at points where I felt participants were more comfortable in the relationship.

4.5.2 Conducting an interpretive conversation: sensing and connecting

The purpose of the interview was not just to hear the words participants spoke but to interpret meaning (verbal and non-verbal) to understand life stories. In this respect, active interviewing is an interpretative act. The general texts on life history interviewing (Atkinson, 1997; Cole & Knowles, 2001; Plummer, 1995; Roberts, 2002) provide useful guidelines to enhance the knowledge production. These include:

- ◆ Listening with curiosity as the key
- ◆ Keeping an open-ended, non-directive, and flexible approach
- ◆ Acknowledging the uniqueness of each interview
- ◆ Practising interviewing techniques such as funnelling
- ◆ Being responsive and attentive to facilitate ease of conversation
- ◆ Being *au fait* with the participants' style of speaking and language use
- ◆ Being able to deal with resistances and difficult moments in the process
- ◆ Attending to participants' perspective in a non-judgemental way, with the intention of facilitating understanding
- ◆ Attending to power imbalances in the research process

However, there is no one way of interviewing and therefore each researcher develops a particular style and sensitivity. Here I have been influenced by feminist methodologies (Anderson & Jack, 1991; Fine, 1998, Josselson, 1995), which promote empathetic meaning-making. I use two terms "sensing" and "connecting" to explain how I approached the *refined nature of the interpretative process*.

I understand "sensing" as an interpretative practice that does not stop at listening but involves a combination of all sensory input and "more" to understand. This could be regarded as an intuitive, extrasensory stance to interpreting the conversation. My task was not just to listen to the words but also to remain sensitive to what participants were saying and importantly, what all of this meant. The tone of voice, emotions, silences, gestures, body language and words were all combined, as sensing became a core aspect of the interpretative process. As I actively constructed

meaning with participants, I fed the sense I made back into the research conversation for further discussion.

I had to process the meaning I was making through my own subjectivities therefore rendering the process as intersubjective. I had to *connect* with participants. How was I doing this? On what basis was I to connect? I am not a PWS and I know the dangers of "Othering" (Fine, 1998) in the process. It was imperative that I understood their stories and yet I could be perceived as an outsider. Did I have to construct the PWS as Other, as different to me because they stutter, or the same as me because we shared many commonalities? Did I want to negotiate this interaction on the basis of the theory that was floating in my head? Which Theory? Sociology theory which I was beginning to enjoy, or Speech Pathology theory which I knew well? I couldn't pretend to be atheoretical. I felt I needed to use all of my resources to "connect" with the participant's experience.

There was no simple way to resolve these dilemmas that continued into the interpretation process. I adopted a commonsense approach. I firstly attempted to connect with their experience through my own multiple subjectivities. I also made overt how my understanding was being shaped, and invited participants to reinterpret and interact with my interpretation. If I was intending an intersubjective understanding then I had to "let myself in". It was important to shift away from being an objective outsider/spectator toward a position where I could stand "with" participants to create understanding and foster an empathising relationship. A useful strategy for me was to "connect" with participants through my own experiences which may have some resonance with theirs even if they were not identical. One example is a women feeling under threat in the presence of male authority, or feeling powerful in a context in which I was in authority. I also used a strategy of "imagining from multiple positions" (Josselson, 1995) how it could be, being lonely or feeling happy and normal as a child on a playground. However, I could never have claimed to stand in their shoes because I don't think that is possible. My intention was to get as close as possible to understanding their experiences.

At the core of all the issues that are critical to the telling of personal stories, is that of trust. It is a dilemma that was difficult to resolve. How would I know that the relationship was a trusting one? I would never know, and so I attempted to create a situation conducive to a developing trusting relationship. My intention to foreground the issues of equity, partnership, collaboration, consultation and transparency were

intended in the interests of “democratic faith”. I reflected on these issues throughout the process (Appendix H) with intent to monitor whether I was encouraging a trusting relationship.

To enhance the sensitivity during the process three suggestions made by Anderson & Jack (1991) and Frank (2000b) were particularly useful. Firstly, it was necessary to listen to the participant’s *moral* language. When participant’s said, “I feel embarrassed, I feel like a failure, I work against the odds,” they were introducing a moral element into the discourse. These moral self-evaluative comments in turn provided an opportunity for me to explore the relationships between self-concept and cultural norms and general expectations of how society expects one to behave (Anderson & Jack, 1991). Listening to moral imperatives of what constitutes “good” and “bad” in context, and the choices participants make in their lifeworlds, allows the space to honour their individuality. As a researcher I felt that it was important to preserve and foster this freedom because it allowed me to understand how participants came to value, devalue and construct their experiences through their own stories.

Secondly, it was necessary to interpret the participants’ meta-statements. These are the places where the participant stops and reflects on what was said. I became sensitive to the participant’s analysis of the discrepancy between what should be done and what they did, or between what they thought was correct and what was society’s expectation. I gained insights into how participants can struggle with dominant frames of reference that construct them as people with pathology and their challenge or submissions to them. This created the space for working within their own frames rather than public validation frameworks.

Thirdly, it was important to listen to the logic of the narrative with the intention of noting contradictions and internal consistencies and themes. For example, those who said they were living successfully with stuttering, told stories which showed how they reached this point. However, I was also aware that because there were dominant and competing discourses, contradictions were not a bad thing. Contradictions should not lead me to doubting the participant but rather offered opportunity to explore the nature of such contradictions. This allowed me the opportunity to appreciate the difficult and complex spaces participants lived in and the choices they made. In this way the intersections between personal and social interfaces became more obvious to me. The stories were not neat and straightforward and required that I probed

various aspects with the intention of establishing coherence by establishing the links between different parts of the discussion.

4.5.3 Power in the research relationship

The issue of power asymmetry in the research process including the interview is an inescapable reality that had to be addressed directly, at the outset, with participants and reinforced throughout the process. While it was impossible to achieve complete equity since the project was mine and I had invited participants and devised the schedule, attempts were made to minimise and raise awareness of imbalances and dominance.

The most obvious threat to the imbalance was that I was engaging in a process with PWS. Traditionally, people with disorders or disability have been constructed (by professionals and researchers), as people on the margins with “less power”. However, I felt it necessary to set the stage for the interview by inviting their stories and encouraging their positioning as expert on their lives. As the interview proceeded I was aware of imbalances and dominances between participants and myself as we discussed particular issues. I appreciated that neither of us could be neutral but also that the purpose of the research was to understand the participant's story. It was necessary to be respectful of different points of view and to keep the intention of the project in focus.

My fear was that I would commit symbolic violence (Bourdieu, 1999) by becoming dominant during the process by the very words I chose and issues I emphasised, without participants or myself being aware of this. Because my own frame of reference had been shaped historically by the medical model, there remained the threat that it would become the dominant frame and that I would do exactly the opposite to what I intended. I felt I had blindspots of which I was unaware, and therefore engaged a fellow researcher to review how the interview was unfolding by listening to the audiotape. I received critical feedback from my research colleague who has experience in life history research. She commented on how I was enhancing and limiting the interview, for instance, in the words I chose, the issues I expanded and the issues I left unattended. In some cases I was made aware that I probed aspects because I wanted to know more about a particular issue which was not important to the participant. For example, I asked about therapy experience in detail when it was raised only as a minor issue by the participant.

4.5.4 How the interviews unfolded

Participants were different people telling different stories and the process unravelled differently. I used a chronological structuring in parts but this was not strictly sustained through the interview process. Some participants talked freely and abundantly while others were less forthcoming. Each interview was customised. I stopped when I sensed a participant was tired, I did not force discussion of issues that participants were reluctant to pursue. I came back to many issues for clarification. It was important to allow the space to go backwards and forwards, to allow participants the opportunity to think, reflect and develop their points of view. The process was one of story-in-the-making (a sample of an interview transcript is available in Appendix I). It was not just a ready-made story to tell and so participants were allowed time to think, reflect, revisit and reinterpret issues, as they felt necessary.

Participants raised different issues and the weighting of emphasis was different across interviews. Some placed more emphasis on current experiences, others on critical events, others on early experiences. As a means of exploring I did what Plummer (2001) describes as “grand tours” and “mini tours”. Participants told me about a particular experience or time period in a general way about an episode. After I gained a general understanding of the emerging issues, I raised the specific issues to gain a fuller and detailed account of the episode. I used the issues they raised as a basis for exploring and illuminating the process of scaffolding, that is, building on what was available through the interviews (Antoinette, 2000). I began each interview by ascertaining the vantage point from which the story was being told, for example, someone who became a grandfather and was experiencing great joy or someone who had just changed jobs, as this had a bearing on how the story unfolds. I relied very little on the interview schedule.

All the interviews were recorded using a small, battery-operated Panasonic mini cassette recorder (RQ-L30), placed between us. I felt that participants were distracted by the cassette recorder initially, but seemed to “settle in” after the first few minutes. I was vigilant about ensuring battery life, proper marking of audio cassettes and equipment maintenance. The time for each interview varied. A minimum of three interviews was scheduled with each participant. Each interview ranged between 90 minutes to two hours. The interview time schedules for each participant is in Appendix (G). Upon conclusion of the interviews, I maintained contact with



participants telephonically or by mail to advise them of how the project was progressing.

4.5.5 Memo-writing in the research process

Throughout the research process I used the strategy of memo-writing recommended by Charmaz (1995a) and Flick (1999) for documenting my concerns, observations and reflections on the process (Appendices H, M, P). During the interview process memos served to track issues which received emphasis, and those requiring further exploration. I also noted points of emphasis, those that appeared emotionally-laden, and the actual descriptions and words used so that I could use their terminology as a means of scaffolding the conversation. After each interview I listened to each cassette noting points where the interview proceeded well, and where it didn't and why this was so. Memo-writing assisted in enhancing my interviewing skills and documenting the emerging themes. While memo-writing does not resolve problems, it provides an opportunity to engage actively with issues during all aspects of the process.

Section Three: Data Analysis

In this section I discuss how I generated the transcripts and how the three levels of the data analysis unfolded. The issues of data representation, individual case and cross-case analysis and theorising processes are problematised.

4.6 Generation of Transcripts

Having completed the initial set of interviews, it became necessary to consider how the data would be managed further. The generation of transcripts was the next logical step requiring careful decisionmaking, given the multiplicity of conventions which exist about the theory and method of transcriptions in the research process (Lapadat & Lindsay, 1999). Each researcher makes a choice about whether it is necessary to transcribe, what should be transcribed, and by whom, in the context of the project (Easton & Fry, 2000). I was guided initially by Bloom (1993: 152), who suggests that the main intention in transcription choices is to provide a "lean transcription" that allows "rich interpretation". I attempted to transcribe the conversation in detail by capturing all the details like disfluencies, silences, laughter, tone of voice etc. This proved to be difficult and cumbersome and I felt that despite

the detail, the transcripts failed to capture the reality and complexity of the conversations. Kvale (1996: 166) describes the limitations of transcriptions by suggesting that they are “artificial constructs that are adequate to neither the oral conversation, nor the formal style of written texts”. Given that the transcript will never be a faithful copy of the interview (Denzin, 1995), I opted for a verbatim transcription of *what* was said or the actual words used in the research interview. In the representation and analytical processes I *combined* my readings of the verbatim transcriptions with memos and listening to the audio recordings, to generate an interpretive understanding. The transcriptions therefore served the purpose of representing in written form the actual spoken words of participants and myself.

After each interview a verbatim transcript of the interview conversation was generated by myself assisted by a qualified speech therapist who had received prior training with transcriptions. The words spoken by the researcher and participant were transcribed verbatim and laid out in relation to the turns taken in the conversation. The transcriptions were also checked for accuracy by an independent listener to ensure the content details were accurate. One participant who had severe fluency agreed to assist in generation of transcripts as a means of improving accuracy of transcription. The next step was to analyse and re-present the data.

4.7 Analysis: Guiding theoretical influences

There were *three levels of analysis* in this study (Fig.2). The first level of analysis was generated via an interpretation of the interview data, memos and listening to the audio-tapes. This initial level of analysis was a narrative analysis (Polkinghorne, 1995) of each of the seven cases. The story served as a data representation device. The research story is the outcome of the first level analysis. The second level of analysis involved a cross-case analysis for the purposes of theorising from research stories and interview data. The third level analysis was derived from engagement with the second level analysis. It constitutes the abstract theoretical offering made in this study which is not case-specific. In the ensuing discussion I explain how these processes unfolded.

The process as a whole was guided by *metatheory, broad intentions of life history research and reflexive analysis*. The analysis process was a struggle for me because it entailed a configurative understanding of a combination of personal, social, political and temporal dimensions. It was necessary to understand the practical implications

of metatheory in the analysis process. I acknowledge that this may be regarded as straightforward and a routine part of what researchers are expected to do, that is to work with a particular theoretical orientation.

In my view metatheory is useful because it promotes creativity at the interface of the empirical material and analysis. For example, postmodern/poststructural theory reminded me to keep issues of multiplicity and fluidity alive, and to keep open the idea that there were many possible interpretations. Each time I looked at the data I saw different things and therefore the offering I make here is one possible interpretation. Critical theory alerted me to the issues of institutionalised power, power within society and the value-laden nature of language data. Metatheory helped me to keep foregrounded the issues that had concerned me about traditional research and reminded me of the contradictions, multiplicities and dynamism. Without metatheory (however problematic it may be), the data ran the risk of being understood simplistically and could mean nothing. In this regard the “mundane” everyday story could receive richer interpretation. I was guided by Alvesson & Skoldberg's (2000) clarification of the role of metatheory which enhanced my understanding of the interaction between empirical material, interpretive repertoire and metatheory (Appendix J).

I had chosen a life history methodology and therefore it was necessary for the analysis process to maintain a resonance with this theoretical lens. In this regard I remained guided by three key issues. Firstly, the individual account had to receive meaning within a socio-cultural context. Among the issues which should be considered (Pamphilon, 1999), are the impact of dominant discourses in shaping experiences; the impact of important historical events which help to shape the link between the individual and society. Pamphilon (1999) also suggests that the researcher should be alert to the type of cultural narrative which emerges when considering the life story as a whole. For example, different narrative types may emerge, e.g. in western literature typical forms include epic (depicting conformity), romanesque (change through progress and individual challenge) and picaresque forms (narratives which challenge hegemonic values), according to Chanfrault-Duchet, 1991. Secondly, because life history is a biographical methodology, it was necessary to analyse the particulars of the individual cases to maintain a healthy biographical and particularistic analysis which I present as the first level analysis. Thirdly, it was important to retain a developmental approach as a means of showing changes over time (Reddy, 2000).

Although I have presented the data analysis process sequentially, I reinforce the *iterative* nature of the process. Throughout the research process I constantly went back and forth between the research stories, the transcripts and recorded interviews in generating the analysis. After I prepared the research stories and received feedback from participants, I returned to the interview data and continued to scan and select aspects that had not received adequate emphasis. I deleted aspects which did not seem relevant to responding to the critical questions. I assembled and re-assembled the stories at least seven times after gathering further information and being guided by peer-review. The analysis was therefore guided by a *reflexive-iterative* stance which unfolded as a series of processes which I present here as the first, second and third levels of analysis.

The first level of analysis involved an interaction with the empirical data i.e. the data produced in the interviews in the context of critical questions. The second level was an analysis of the underlying meaning of the data produced in the interview whilst the third level entailed generating abstractions from the second level analysis. However, *there was a constant interplay* between the empirical data and levels of analysis (Alvesson & Skoldberg, 2000). This interplay affords the opportunity for the data analysis to be strengthened by a combination of interactions between and among theoretical perspectives and processes at different levels of analysis (Fig.2). The unfolding analysis requires a combination of data-driven and insight-driven processes which combine interactively to enhance the interpretive possibilities.

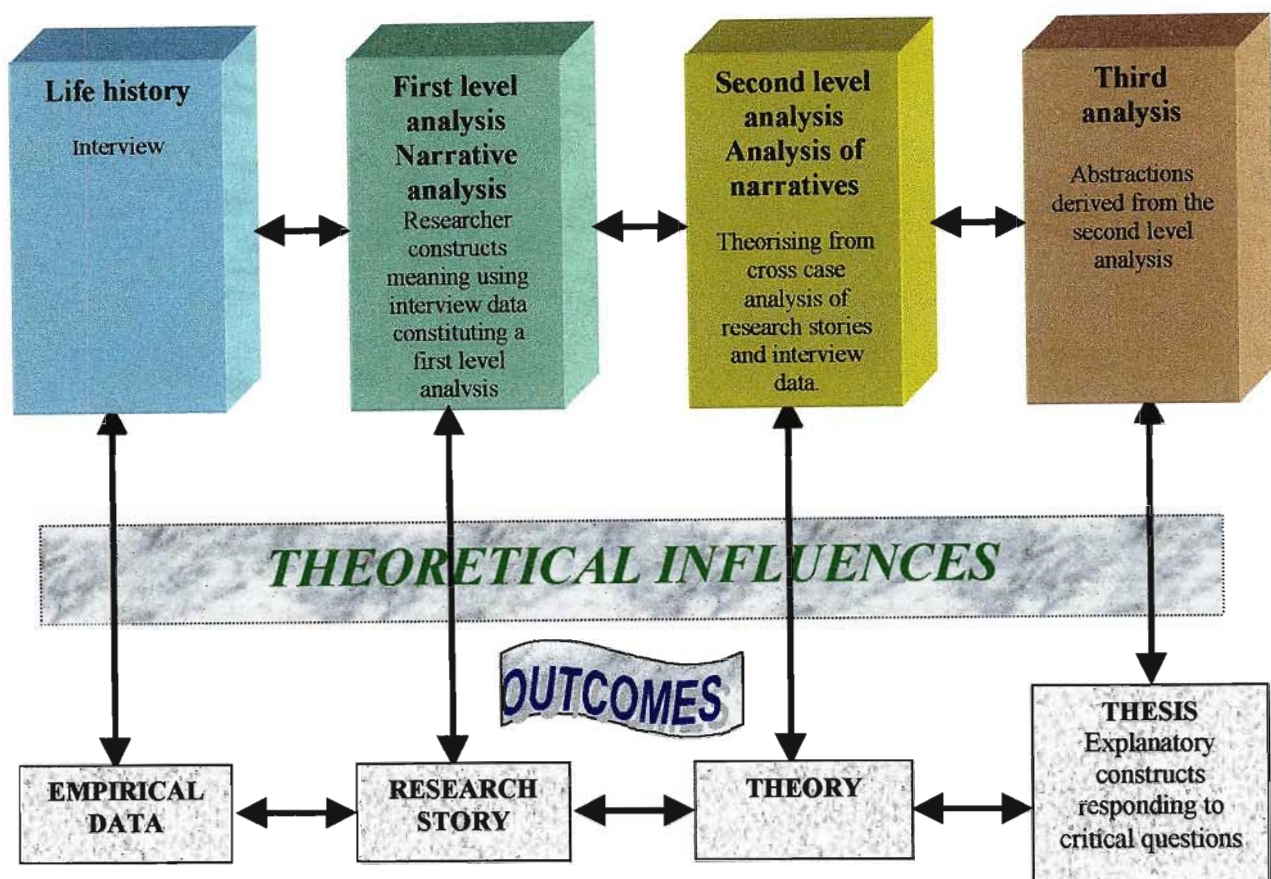


Fig. 2: Interactions: Levels of analysis, Theoretical influences and Outcomes

4.8 First level analysis

There were two decisions I took at this point as I contemplated the formal analysis. The first relates to the decision to conduct a *representational* analysis and the second to use *story* as a *representation device*. Freeman (1996) distinguishes between representational and presentational analysis when using language as data. Representational analysis refers to “what was said,” whereas the presentational analysis refers to “how it was said.” These processes are interrelated and complement each other. I chose the representational analysis because the study has an interest in what was said about identity formations and experiences. However, the “how” influences “what” in substantive ways and the presentational analysis is embedded in the representation task. The specifics are detailed later in this section.

Secondly, I decided that a *narrative analysis* would be preferable because I was analysing life stories and not reports or responses to a questionnaire. I use

Polkinghorne's (1995) notions of narrative analysis grounded in Bruner's⁵ theory of two modes of cognitive functioning to differentiate between narrative analysis and analysis of narratives. Analysis of narrative privileges a paradigmatic reasoning, whereas narrative analysis relies on narrative reasoning in considering narrative interview data.

- ◆ In the 'analysis of narratives' data are analysed using paradigmatic processes wherein common themes are traced across stories, characters or settings. In 'narrative analysis' the raw data are configured by means of a plot into a story, thereby moving from *elements to stories*.
- ◆ The outcome of the data analysis process is an emplotted narrative or a story. In this study I have chosen story as a re-presentation device because of its utility in holding together disparate, complex and interrelated aspects of the data produced.
- ◆ I use the term *research story* because the stories have been generated in a research context. They are based on empirical data. The researcher's task is to construct a story using data elements that unite and give meaning to the data using a narrative structure. The researcher engages in a generative discovery process by interacting with the text and data in an iterative process to generate the research story.

I was also aware that there are many other representation devices such as writing poetry and drama, which have become popular particularly with post-structural and deconstructionist researchers (Abma, 2002, Larson, 1997). I chose to retain the story supplemented with verbatim transcriptions in the text because I felt that the story as a representation device was suitable, creative, and useful in the context of this study. Extracts of the verbatim text support the second level analysis by providing a direct account of the participants' voices to enhance the credibility of the analysis. I did not pursue further representation possibilities but acknowledge their potential.

⁵ Bruner (1986) Bruner distinguishes between two modes of cognition viz. story and argument. Each provides distinctive and irreducible ways of ordering the world. Whereas argument convinces of a single truth by using traditional principles of formal, empirical proof, the story seek to convince by establishing a lifelikeness intended to produce not truth but the appearance of being truth (verisimilitude). The argument, characterised as the paradigmatic or logico-scientific mode of thought, serves the purpose of explanation by drawing causal links between dependent and independent variables in search of formal mathematical explanation. The story, in contrast deals with human intention, action and consequences, linking events and experiences over time and place.

The choice of narrative analysis and story as a representation device requires the researcher to address many issues (Reddy, 2000) about the purpose of the story, theoretical location, textual representation and language, truth-value, the intended audience, voice, selections, style and artistic devices in constructing the story. A discussion of these issues follows. This process was a novel one for me and the part of the project I found both interesting and destabilising.

The *purpose of the research story*, a biography, is to illuminate individual experiences of stuttering in their lifeworld by understanding how they form their identities and negotiate stuttering over time. The research story is therefore constructed with intent to answer the critical questions. As such it is analytic-descriptive in nature because it address critical questions whilst providing the descriptive details of each participant in context. The research stories are structured chronologically to explain a particular endpoint in each biography. The connections with the research story were not necessarily linear but combinations and accumulations of events, responses and actions that explain a particular end. The product is reflective of a temporal ordering in which each part is given meaning via its reciprocal relationship with other parts, before and after, and to the whole. The plot functions to compose events into a story (Polkinghorne, 1995) by:

- ◆ delimiting the temporal range which marks the beginning and end of the story;
- ◆ providing criteria for the selection of events/issues to be included;
- ◆ providing temporal ordering and unfolding of events leading to a conclusion and
- ◆ clarifying the meaning events have as contributors to the story.

In producing the research story the researcher therefore draws on her theoretical expertise to make sense of responses and actions. The process requires extensive engagement with the interview data and is influenced by the theoretical stances of the researcher discussed in Chapter Two and Three. The research story in this instance resists any specific theoretical location, for example psychological or sociological, because it is inherently interdisciplinary. It can be described as having a life history orientation in that the social, personal and temporal lenses have been actively appropriated in the construction. It was also theoretically orientated to reveal the intersections between the *personal and sociological dimensions* of experience in illuminating the issues of stuttering in society. I have an interest in an *active* story about living with stuttering with an *ethical* obligation to illuminate what *participants*

thought was important to them and explaining why they chose to act in particular ways.

An immediate concern in writing a research story is the question of truth-value when shifting from the interview data to the research story. I am interested in the personal truths of participants. However, these truths about the individual's experience are manufactured within the context of the dialogic interview. Some narrative researchers therefore see their roles as similar to artists who reconstruct a situation to convey something about it (Lawrence-Lightfoot, 1997). Other researchers contest the issue or refer to truth-value by using terms such as believability (Lawrence-Lightfoot, 1997), credibility (Polkinghorne, 1995), or fidelity (Blumfield-Jones, 1995). In what remains a debatable issue I considered the plausability of the plot and the issue of coherence in the story as two ways in which to reflect on truth-value. The plot is constructed after the researcher has been immersed in the data and it is the *explanatory potential* of the plot I considered to be a means of gauging truth-value. I was guided strongly by the fidelity of the plot with regard to what the experience was like for the teller of the tale, that is, as experience in the context of a particular life, showing a faithfulness to the teller.

A further dimension of fidelity comes through the researcher constructing a larger network of personal, social and historical relationships. She has the responsibility of weaving the personal story into a more complex set of social issues. It is here that the issue of truth and fidelity becomes more complex because the researcher has the unenviable task of locating a personal narrative within a social context and while doing so, runs the risk of losing the original teller's perspective. The task of bringing together both the individual story and social context is the challenge of writing an interpretive story (Goodson, 1995). In all research stories there was a deliberate effort to locate participants within their contexts. I did this by gaining insights into the nature of contexts during the interviews and knitting them together as a plausible plot. I highlighted the time period in which the story unfolded, the place/s in which participant's spent much of their time and the significant sociopolitical events, social discourses, value systems, and participant's interpretation of how these influenced them at a personal level.

The coherence of a story is an important consideration especially for life history researchers who have the task to bring together a coherent story spread through time (Mishler, 1999; Plummer, 2001). The traditional notion of a coherent story is a

single, neat unfolding trajectory in which the actor acts consistently, has been challenged within poststructural theory. I agree with Mishler (1999) that the interpretation of coherence in a research story should be revised to admit multiplicities and non-linearity. It is this story which is more likely to be coherent within social and personal realities that are changing. A complicated coherence? Mishler (1999) explains that traditional notions of coherence have been challenged in text-centred linguistic domains by linguists, as they have moved beyond the structural features of discourse analysis. There is an "intuitive" understanding the researcher must have in reviewing different parts of the text, to create coherence from a seeming randomness. Shiffrin (1994, 1996) suggests that coherence cannot be limited to linguistic forms and meaning but that it should be understood within a broader context of social and cultural meanings evident in discourse. My interpretation of Shiffrin (1996) and Mishler's (1999) stance is that "coherence" should bring together disparate, multiple, shifting, contradictory and seemingly random elements of a story to create a "complicated" or "fractured" coherence within a social frame. This stance overlaps with Blumfeld-Jones' (1995) understanding of fidelity. The story should be coherent within an approximate of the "complex" lifelikeness establishing not truth but verisimilitude, the appearance of being true (Bruner, 1996).

Although the researcher is the writer/author and the participant is the storyteller, the data was jointly constructed between two unique individuals. Therefore, it is sensible and fair to suggest that the participant should also contribute to establishing the credibility of the research story. In this study the participants were invited to review the research story and to influence it so that it was faithful to the meaning generated in the interview process. The details of the review process appear later in this discussion. Furthermore, the persons who assisted in the transcription process, as well as my research colleagues, were asked to review the truth-value in moving from interview data to stories. Through various inputs the research stories were revised with intention to enhance their "truth-value".

Stories are written using language which offers opportunities for representation but which can be simultaneously constraining. The issues of textual representation have been debated in the domain of postmodern research (Abma, 2002; Lather, 1991; Rhodes, 2000). Lather (1991) uses Derrida's deconstructive theory and explains that language cannot claim to "mirror reality". The inner life of an individual is filtered through the glaze of language, signs and processes of signification. We are born into

a world where language is available and we appropriate such language to construct meaning. Therefore, language in itself is not neutral but is a social vehicle for creating particular realities. The language used by participants was an important consideration in story construction because participants have a particular set of discourses available to them by virtue of living in a particular social world. The stories therefore do not mirror lives but create realities. Therefore, in engaging with data the researcher must attend to the language the participant uses to get an impression of how the story links to the social world and make decisions about the language she uses to construct the research story. However, language can also be constraining because it may not be able to adequately address some dimensions of human emotion such as suffering, which resists “knowing”. In the research contexts participants say “I don’t know how to explain this” or “words fail” which are indications that language is also constraining.

The research story was *interpretive* in that it wasn’t just a verbatim recording of words but rather a documentation of the meaning created through our conversations. The “linguaging” of the story included an interpretation of textual and non-textual cues in meaning-making. In the first version of the stories I wrote in the first-person, I did not attend sufficiently to the participant’s exact words and style. Participants agreed with the interpretation but were somewhat confused about the voice; it was their story but not as they would speak it or write it. I rewrote their stories relying closely on their words and style of speaking but keeping the interpretative element. In this way it sounded like them, speaking in their style and words. I was guided by Fairclough’s (1989) critical discourse analysis framework (Appendix K), as a means of heightening my awareness of “how” participants spoke, thereby integrating a presentational analysis. An important consideration in this study was about representing stuttering as a dimension of the participant’s communication. For each participant only a small part of the text is devoted to the presentation of stuttering, given my intention to deliver a representational analysis.

One of the key issues considered was whose voice the story was to be written in. The options included first-person, and third-person narrator, with the researcher as the writer and the participant the storyteller. I explored two voices for the purposes of representation and discovered that they both have value and limitations. My initial draft during the pilot phase was written in the third-person supported with direct quotes (Appendix C) made by the participant during the interview. I found this voice useful because the researcher’s voice is obvious as she analyses the story (Samuel,

2001). I then experimented with writing the story in the first-person account that accommodated the descriptive and analytical elements. This voice seemed more “authentic” because the participant's words and style could be represented making the research story more life-like. With this choice, however, the analytic voice of the researcher can be muted. However, I felt that the research story should remain close to the voice of the participant, especially because I had an interest in issues of self-identity formation in this study. It also seemed easier to read the story about identity formations when narrated from the various I-positions, that is, in the first person.

The stories were then written by considering what was said: the content and how it was said, thereby combining presentational and representational elements. In the interview, participants talked about many things and it was necessary to select events and issues for inclusion in the research story. These selections were informed by what participants emphasised during the interviews. However, to construct the research story, I re-read each transcript many times over and carefully reviewed and revised the selections with the intention of responding to the critical questions. In this regard I actively selected aspects of the interview to create a research story with a plausible and coherent plot with intention to answer the critical questions.

A story is meant to be interesting and should engage the reader. Was this true for a research story? I felt that *artistic techniques* which would help to illuminate the personal truth-value of a story required exploration. Blumfeld-Jones (1995) suggests that artistic representations can enhance the fidelity of the research story. I was enthused by the creative and artistic suggestion made by Barone (1997) and the motivations provided by Richardson (1992) and Denzin (2000) about the interesting ways in which researchers can stage texts to provide interpretation and provoke discussion. I felt the “giddiness” Barone (2001) talks about when researchers are released from methodological straightjackets. I wanted the stories to be *alive* in the interests of enhancing scholastic potential (Abma, 2002) and therefore used common literary devices such as figures of speech (similies, metaphors, hyperbole, and rhetorical questions), repetition, irony and understatement, purposely writing in the present tense. In addition, the presentation was “smoothed” using techniques suggested by Spence (1986).

Barone (2001) extends this interest in advocating for the use of fictional techniques based on Maxine Greene’s persuasive stance on how imaginative literature can

serve us well in understanding our lives. He argues that if all stories, including research stories, are fashioned by human beings, then they are all, to differing extents, fictional. He coined the word *factional* to blur the boundaries between fiction and fact. While the empirical story, the “inside” story, provides the “fidelity” requirement, or an honest version of the participant’s experience, there is the external story which can be fictional in that it contains a mixture of real and unreal (imagined) events. This is possible because stories are active creations between participants. There are often incomplete scenes that the listener “fills in by imagining” or makes sense, based on her own experience. Could it have happened like this? When such dialogue is invented it is *critical* that it is done with intention to serve a legitimate research purpose. The text should serve the end of generating conversation as good stories should invest in ambiguity and should not conclude.

In agreement with Barone's suggestions I experimented with *fictional techniques* in writing the research stories only at points where I felt that their use would enhance the significance of what was being said. For example, if a participant placed repeated emphasis or spoke about some issue emotionally to convey its sense of importance, then fictional techniques were used to amplify the meaning. The kinds of techniques used included: recreations of scenes, making them “full-blooded” through the use of imagery and choosing words which helped to convey the emotionality and meaning. At some points there were subtle elements in the story, or throwaway comments that shaped the story in a significant way. These were also illuminated through the use of fictional techniques occasionally by recreating scenes in the research story to offer clarity of the points being made. However, I did not retain the fictional elements when participants felt they did not enhance the meaning of the story or indicated that they were uncomfortable with it. In one research story (Kumari’s story), the participant insisted that the fictional and interpretive story was a better representation of her story than she could “say in her own words”. She therefore felt that her research story should be retained using fiction techniques where necessary.

The research story included *other data sources*, where available and relevant, but did not serve as primary data in this study. I included data from other sources admitted by participants. For example newspaper articles, video-recordings, letters, curriculum vitae and photos. In keeping with my intention of developing intersubjective understanding, I sought to obtain the participants’ interpretation of additional data sources in the context of their stories. These interpretations were woven into the representation. For example, a participant would bring along a video of speech—

making, or a letter written by someone other than himself or herself. I was interested in his interpretation of these artifacts within the context of his story.

As I have already mentioned, I invited participants to *review* their research story and also to offer analytic commentary. I provided them with information about how the research story was constructed and its purpose and asked for their comments regarding analysis. The guidelines presented to participants appears as Appendix L. Having written the research stories and presented them for review, I became very concerned because I didn't know how participants would respond. I was anxious about whether I had understood and represented their experiences in a faithful and sensible way (Appendix M). Their responses were varied and the issues raised in the story review process were very interesting and contentious. In the context of this study I cannot do justice to the theoretical debates which emerged, as these issues are complex. Here, I summarise only the key issues emerging in the review process:

- ◆ Some participants felt that telling their story and reading their stories were very different processes. Reading their lives was not a simple process because a whole life experience was summarised in few pages. As a consequence, the interpretative account was a “harder and sharper ” account. One participant explained that reading the story was like “going back to the scene of the accident”. There was nothing that was untrue but it was vivid and sometimes “difficult to look at”. He suggested that some “sharp edges” be revised.
- ◆ The use of fictional techniques and other literary devices were received differently. Two participants described it as dramatic but making their story more “real” than less “real”. However, they also drew attention to the fact that it didn't sound like their voices in some parts, while in other parts it was very close to how the experience unfolded. Five participants suggested that the interpretive story was a close, intuitive account. They recommended that the artistic techniques should be retained because it enhanced the meaning of their stories.
- ◆ Editorial and other corrections were brought to my attention, for instance, incorrect names or times, or something that happened in high school which I had placed in primary school.

- ◆ The review process afforded the opportunity to extend the interview process to generate a more sharpened analytical interview, which produced additional data. I was able to revisit key issues and clarify aspects that needed further discussion. It also provided an opportunity for collaborative participation because participants were actively shaping the story and contributing to analysis.

- ◆ One participant requested that some words be removed although he had used them in the interview. He felt that the written story was more formal than the spoken word. He also queried my deliberate foregrounding of his race and socio-economic status. I explained that the stories were intertextual and required grounding in a social context. Therefore, issues of race and class had become apparent in the story. After our discussion he understood the intention and in recognising the importance, began to elaborate further, providing very useful additional information about the particular time period. Another participant requested that an incident involving his "failing" to be removed, because it "spoiled" his story. However, when I explained that it was one of the incidents that shaped his life story, he agreed to leave it in since that this was a research story.

- ◆ One participant was unavailable during the review process because of his busy work schedule. I asked a fellow researcher to review the story and transcripts to ensure that important details were available. However, the difficulties with maintaining prolonged engagement are acknowledged. Participants provided different types and levels of input. I think it is possible that some participants may not be interested in every step of the research process. I felt that I had fulfilled my obligation by inviting participation and that participants had the right to choose whether or not they wanted to participate.

All these comments and discussion revealed to me that the writing process is not an innocent one. It was an occasion for me to reflect on the power of the written word and how dangerous constructing research stories can be. On receiving feedback from participants, I rewrote the stories using a significant proportion of actual spoken words and specific styles of speaking of the participants. I was guided more strictly by Fairclough's (1989) framework because I had chosen to write the research stories in the first person. The interpretative stance was maintained and the research story served as a first level analysis. I asked participants to comment on the revised version of the stories. Minor changes were suggested and these further revised versions are presented in Chapter Five as research stories.

4.9 Second and Third level analysis: Generating theory from research stories

Thus far, I have explained how the individual biographies were constructed. The seven research stories about life experiences of stuttering are unique, unfolding in KwaZulu-Natal, SA, during a time period between 1936-2001. In moving to the second level analysis, I used all seven research stories for the purposes of explaining how and why their identities formed over time, and how and why they negotiated stuttering. There is no single way of conducting such an analysis. However, the process was informed by analytic induction and grounded theorising as discovery-oriented approaches to analysis of qualitative data (McMillan & Shumacher, 2001). In the context of life stories, the process was an intuitive one in which I intended to develop a configurative understanding of the unfolding experience.

The grounded theory approach to analysing qualitative data has roots in the work of Glaser & Strauss (1967), who have a sociological background. The strict application of the original method has not been applied (Plummer, 2001), especially in life history research. Here the single long case is not amenable to the traditional notions of theoretical sampling, where the researcher moves from one sampling source to the next according to strict theoretical criteria. However, the main emphasis of *discovery of theory through rigorous engagement with the empirical data* has remained as an important guiding principle in qualitative research (Alvesson & Skoldberg, 2000) and was retained here. The inductive nature of analysis assumes an openness and flexibility in the process wherein the patterns and issues emerge from the data. Although the researcher does not engage with the data *tabula rasa*, (Charmaz, 1995b), it is important not to force preconceived ideas into the data analysis process but to nevertheless interact with theory for the purposes of enhancing it. In this study I was guided by Charmaz's (1995b) orientation to grounded methods of theorising, which include the application of inductive strategies for the purposes of engaging with the data.

The process of grounded analysis did not begin at this point but were embedded in the interview and story construction processes. My intention was not to be guided by *a priori* theoretical categories or constructs but to rely on the empirical data to generate possibilities. The process therefore began with a close reading and rereading of data. During the immersion process, which continued through all levels

of data analysis, I found that I studied different facets of the emerging data (after the interviews) in many ways and for varying purposes.

I first listened to the audiotapes for the purposes of transcription and to gain a general understanding of the stories. I then reread the transcriptions again, checking for accuracy. The third time I listened to the tapes and reviewed transcriptions was to generate an interpretative understanding and coding data. The fourth time was to attend carefully to word choices, tones and emotions, what was repeated and what was not said. After the story revision I reviewed the data again and continued to do so throughout the analysis process. Having read and listened to the interview data many times, I found that I became very familiar with the stories. The continued immersion in the data allowed me to generate new and different ideas. I also combined the emerging empirical understanding and theoretical with intention to theorise creatively. For example, the experiences at school emerged as significant, but it became necessary to problematise this issue by understanding the school as a social institution and examining the power dynamics embedded in the experience. I was also guided by the issues that participants thought was important in their research stories in forming my analysis.

During the initial stages of analysis my own frame of reference was limited. Having expanded my scope of understanding to various narrative and social texts I was able to read the data differently. I remained guided by issues of variability, multiplicities and discontinuities, rather than only on seeking stable, coherent patterns across the data. At points, I realised that I slid towards seeking only regularities and that this did not serve the data well. I therefore remained vigilant about remaining grounded in empirical data. Life history data are rich and complex and I sometimes found that I was "laying out or separating the threads" rather than discussing the complexity of the mesh.

I approached cross-case analysis using a process of constant comparison between the cases over time in relation to emerging themes and issues or variables. This could be described as a mixed strategy which combines the case and issues/variables making it a preferred strategy in the context of life history research (Reddy, 2000). I have structured the analysis chronologically, exploring how various themes unfolded over time. The discussion of each issue or theme is generated via constant comparison between individual cases or by the clustering of cases which share similarities. My intention was to theorise in a way which contributed to

understanding experience as dynamic, human, social and political, that is a “lively” theorising. However, I felt that even these attempts are reductionistic and do not do justice to the complexity of life experiences.

I read across the individual research stories and interview data for the purposes of generating an analysis. I coded chunks of data and searched across the research stories data to find similar or conflicting themes or issues. The emerging themes were clustered and categorised in different ways. For example, I categorised what participants did as children in negotiating stuttering, or what were their most robust responses in a particular context. There was also a need to consider relationships across categories and over time. The analysis process stretched over a period of seven months during which time I moved between emerging issues and the data and made notes. When a theme began to emerge, for example, around issues of identity formation there was also a need to reread data in the context of the emerging issues and categories. As the process unfolded iteratively, there was a constant and intuitive play with constructs and categories across stories. The analysis was emerging in a network of relationships and in multiple layers.

The intention of the cross-case analysis in Chapter Six is to consider the issue of transferability of the emerging issues across cases and to deepen the understanding and explanation of particular constructs or issues by examining similarities and differences. I began by analysing each case thoroughly, in relation to emerging themes. A sample of two such case analyses are presented in Appendix N. The details of the individual cases analysis are not presented in the cross-case analysis. In life history research the cross-case analysis introduces a dilemma about whether the individual story will lose its unique value as one seeks generic understandings across cases. In this study I have attempted to accommodate the value of both these orientations by retaining the specificities of the individual case through the research story (first level analysis), and offering a cross-case analysis as a second level, analysis with further abstractions at the third level. The analysis moved from particular to general issues across cases.

I extend the analysis in Chapter Seven, by introducing a third level analysis spawned from the second level analysis. My intention here was to present a set of abstractions and explanatory constructs which respond to the purpose of this study, which is to theorise life experiences of participants who stutter. The abstractions are not case specific but reflective of the most robust outcomes in the context of the critical

questions raised in this study. My reflections on the “struggle” during the analysis process are presented in Appendix O.

Section Four: Quality in the Research Process

In this section issues of quality are discussed using a framework which considers substantive validating and ethical validating. There have been extensive debates about issues of quality and validity. I have come to understand that any one set of “criteria” or standard for all research is counterproductive, given the paradigm proliferations and vast array of methodologies available. However, this does not mean that issues of quality are unimportant. They should be appropriately addressed within the context of a particular study. I use the framework of ethical and substantive validating (Angen, 2000), to structure the discussion and problematise the issues and pragmatic choices I made. Substantive validating is concerned with issues of trustworthiness and goodness of interpretive research (Angen, 2000) and requires consideration of issues like suitability of methodological choices, credibility, dependability and authenticity trail (Cresswell & Miller; Lincoln & Guba, 1985; Searle, 1999). In contrast, ethical validating is concerned with the moral issues the researcher must entertain.

4. 10 Substantive Validating

4.10.1 Methodological choice

Having developed a rationale for the study I needed to question the suitability of the methodology. In this study I intended to gain an understanding of participants’ experiences of stuttering in their lifeworlds. I was interested in their personal truths. I felt that life history research was suitable for this purpose because it allowed insights into personal experiences over time. The choice of methodology was suitable because I was able to produce data and engage with critical questions. The methodology that allows an engagement with personal truths and issues of identity formation, both of which are critical to this study.

4.10.2 Credibility: How does one demonstrate that the research is credible?

Lincoln & Guba (1985) provide a useful set of guidelines for evaluating credibility, which I appropriate here.

Member checks were done at the following points:

Since it is the personal truth of participants I was interested in understanding, it made sense to use the strategy of member-checking at various points in the process.

- ◆ During the interview process, I consistently checked my interpretation of issues raised, clarified issues and confirmed technical details with participants.
- ◆ I checked the accuracy of transcriptions with participants especially at points where I was unsure of the actual words being used.
- ◆ Participants read two versions of their stories. The feedback from both readings was considered in the final presentation.
- ◆ I offered participants my initial thoughts on analysis and also asked for their comments. Although I did the analysis, I was guided by their input.

Prolonged engagement:

I engaged with the participants intermittently for different purposes during the research process which unravelled over a period of two years. Prolonged engagement allowed time for reflection for myself and participants, the opportunity to produce refined data, clarify aspects they had been thinking about, and in general improve the quality of data production (Plummer, 2001). The total contact time with each participant varied, but a minimum of seven hours was spread approximately four interviews. The relationship therefore is different to one in a once-off single interview. The benefit of prolonged engagement was noted especially with participants who stuttered severely initially, or those who only shared the depth of their stories freely once they felt comfortable.

Peer debriefing:

I consulted with peers during the research processes, namely the development of the interview schedule, the interviews, transcription process, data representation and analysis. Mer-shen Pillay, a fellow doctoral student and speech pathologist was actively involved in critiquing the process at each point. He played devil's advocate,

asked hard questions and challenged me throughout the process. In addition, Ruth Beecham, a doctoral graduate and clinical practitioner, was involved in the debriefing process during the initial phases of the data analysis, story construction and thesis generation. These processes sharpened my skills as a researcher, allowing me to engage reflexively on the process and in this way enhanced credibility as every process was always “in check”.

Thick descriptions:

I accessed specific biographies in particular contexts and provided “thick descriptions” of empirical data represented as research stories. A thick description is one which captures detail, density and depth to create a sense of verisimilitude so that the statements and stories can bring the experience to life. The reader then feels as if he or could experience the events being described (Charmaz, 1999; Plummer, 2001). The details include characterising individuals, detailing actions locating individuals in specific contexts, and describing emotions as presented in the research stories in Chapter Five. It contributes to credibility because the reader has a detailed description of the particulars of the case necessary in life history research. The thick descriptions are important to allow the reader to consider the transferability of issues across settings, by judging the distance between the particulars of the research story against his own context and cases (Samuel, 1998).

Appropriateness of terms of reference of interpretations and their assessment.

I have detailed the approach to analysis in Section Three and the question which remains, is about how appropriate or suitable the analysis was. There is unlikely to be “one best interpretation,” but the analysis I have offered is the “best” I could do for now via processes of intensive engagement with data, theory and peers. Lather (2000) has argued that “good” research should not provide answers but should raise questions and extend debates. Therefore, the interpretation does not pretend to be complete or unproblematic. Each reader will therefore provide his own assessment. In my assessment, the process was rigorous during all levels of analysis, guided by theoretical influences I made overt and remained grounded in empirical data. I revisit the strengths and limitations of theorising in Chapter Eight.

4.10.3 Procedural Dependability: Auditing

How does one make evident that the research process is dependable? I considered an audit trail analogous to a fiscal audit (Lincoln & Guba, 1985), to reveal that the whole process was systematic and rigorous. The audit trail must consider how the steps taken in the context of a particular project enhance procedural dependability (Flick, 1999). I have already addressed (in Sections One, Two, & Three) the specific measures taken to enhance dependability as the various processes unfolded. Here I merely restate how and where these procedures are documented in the text to avoid repetition. The documents I refer to constitute evidence of my claims to enhance procedural dependability. These include:

- ◆ Raw data, collection and recording (memo-writing presented in Appendix H).
- ◆ Data reduction, theoretical notes, summaries and short descriptions of cases (memo-writing and preliminary analysis examples).
- ◆ Reconstructions of data, findings and links to literature (Section 3: analysis).
- ◆ Process notes on methodological issues, concerns and decisions (Sections One, Two & Three and memo-writing appendices)
- ◆ Record of participation and expectations (appendix D).
- ◆ Information on the development of research instruments and pilot project (Section One & memo-writing appendixes H, M, P).
- ◆ The dependability of the processes of data representation, and interpretation (Section 3 & 4).

I used the technique of memo-writing throughout the process for documenting my reflections on the research process as well as methodological details. They also serve to highlight that the process was a difficult, and uncertain one raising many contradictions. These "declarations" are intended to reveal the complexities rather than mask them. At a personal level I felt that the nature of the research process allowed me to be honest, and I attempted to follow closely the available guidelines to enhance dependability.

Authenticity

How can the criterion of authenticity be assessed? One way of considering this issue is to remain committed to member checking but also to ensure that there is an

element of "fairness" (Guba & Lincoln, 1998) in the process. I have presented the participants' issues and concerns transparently throughout the process. The research stories are "authentic" representations of actual events in the lives of participants, as confirmed by them. Even where fictional techniques have been used, they are used only with the intention of enhancing the "authenticity". However, this study is premised on the notions of multiple-constructed realities rather than a single tangible reality. Therefore, the applicability of traditional notions of authenticity is questionable, that is, there is one fixed reality. The data could be represented in multiple "authentic" ways to reveal different issues, all of which are likely to meet authenticity criteria. There is no single "true" story.

4.11 Ethical validating

4.11.1 Nothing is innocent: Maintaining moral responsibility

Angen (2000) argues that ethical validating should be a core concern in interpretive research because it introduces a moral element which must be considered as central in the process. In an effort to attend to this concern, researchers have introduced constructs like beneficence (Kvale, 1996), the need to promote equitable contexts in the research process (Haraway, 1988; Lather, 1992) and a fairness criterion (Lincoln & Guba, 1985), to ensure that the debate is fair and that voices are not demeaned, silenced or that the potential power of the powerful in the process is restrained. The approach should allow researchers and participants to be connected via their shared humanity. I have addressed some of these issues above, but I consider more specifically here, how this responsibility was approached in this study.

At the outset I began with the core concerns I had as clinical practitioner and felt that there was a need to theorise the life experiences of PWS. In this regard my intention was to "do good". However, as Lather (2000) cautions, "nothing is innocent" during the research process, even when there is an intention to do good. I felt that at various points in the research process it was easy to exert my power and shape the process without the participant even being aware of this. Therefore, it was necessary to be fair within a broader intention of equity in the research process. During the interviews I routinely "checked" my interpretations with participants. I also reviewed the interview transcripts with a fellow researcher in an attempt to be more critical of my participation.

I critiqued the audio-recordings by myself (supported by peer-evaluation) after each interview, making notes of where I appeared to be insensitive, influenced the conversation unnecessarily in a particular direction or dismissed issues I should have listened to more sensitively. I also asked the persons involved in transcribing to comment on my role during the interview process. While all of these practical steps were taken, I remain convinced that being interested and human was a fundamental non-negotiable part of the process. I remained respectful, sincere and fair in the best way I knew how. I also asked participants for feedback about the research process as a whole. Most said they felt comfortable enough to share stories in a situation that was non-threatening. They were mindful of the power dynamics but were able to share their points of view. Others highlighted the nature of difficulties they experienced especially during the early period of “settling in” into the research process and their concerns about representation. I felt that the process was transparent and sensitive to the best of my ability.

I also realised that the research process had potential to disrupt participants because they would have to actively negotiate issues that may have otherwise remained untapped. I became increasingly aware that participants might require additional support and counseling after discussing traumatic events or having told a story that was destabilising. It is difficult but important to understand the fine line between one's role as a researcher and a counselor. I separated these roles in the context of this study. I did not want to be researcher and counselor during the process of data production. However, I remained vigilant about the need for additional assistance. At each point in the research process, we discussed these issues. Generally participants did not appear to be in need of additional assistance.

However, the story review process was analytical and highlighted sensitive issues. At this point one participant said he had been unable to continue with speech therapy for logistical reasons and that he required assistance. I supported him at the end of the research process and reflect on this process in the Chapter Eight. Another participant explained that that she was constantly in search of ways of understanding her problems and that the research process had been catalytic in seeking further healing options. She did not feel threatened but was strengthened by this process. The potential and threat of this research process lie side by side. I was on the alert that I could do harm and good. Every research process has potential to touch a subject in some way and there must be a vigilant effort made to reduce harm (Frank, 2001).

4.11.2 Generative Promise

What does the research claim to offer and does it do so?

Good research should raise awareness of new issues stimulate debate and invite dialogue (Angen, 2000; Lather, 2000). Is what I have raised new? Different? And if so, for whom? I have used particular biographies as a basis for generating issues. Some of these issues have relevance for the historical period and context in which lives are lived, and adds "new contextual realities" to the dialogue. Particular analytic concepts, threads and ideas have been generated from the data and offer "new" ideas in that they are unavailable in stuttering research, as far I know. Issues of self-identity formations have not featured prominently in the literature. However, new ideas are never completely new, since I am part of a larger social discourse and draw on interdisciplinary discourses in offering analytical commentary. In an attempt to ascertain the "newness" of the project, I invited dialogue about potential theoretical and methodological contribution from practitioners, students and researchers via conversations, journal publications of initial outcomes of the pilot phase (Kathard, 2001) and presentations at three international conferences. Through these discussions it became apparent that the methodology was, for some, a refreshing addition to the profession (Appendix, P). I am aware that I have only been able to generate new ideas within the limits of my own ever-expanding horizons and that I have just begun this conversation.

At a personal level I am encouraged by the understandings I have made thus far. I have added my voice to a larger body of literature on stuttering. The theorising does not resolve or address all my concerns but has allowed me to understand some issues better. I continue this discussion again in Chapter Eight because I think it is premature to present it at this point. I believe that the generative promise will come out of a much broader process of debate and dialogue and I invite those who read this offering to contribute to it, challenge it and most importantly, to continue it.

4.11.3 Practical value

Does the research offer practical value and for whom?

PWS participated in the project. Did the research process and the issues generated have practical value for them, individually and/or as a collective? I shared my ideas

about analysis issues during discussions with participants. They offered suggestions about how these research outcomes may be practically utilised. Among the suggestions were the following:

- ◆ To publish the outcomes of the study in the local newspapers to raise issues of concern publicly, and to invite discussion.
- ◆ The research stories could be useful for parents of children who stutter because they can understand many issues through the stories.
- ◆ One participant generated a script for a drama to raise awareness of emerging issues. He would like to enact this in the future as part of a community education exercise.

Furthermore, speech pathologists, students or other practitioners in the medically-allied disciplines (physiotherapy, psychology and occupational therapy) may find that the issues generated here have implications/applications for their practice. Researchers may wish to engage with or challenge the methodology in particular, as a means of contributing to the dialogue.

4.11.4 Transformative potential

Through this research process I have often wondered whether the methodological shifts and theorising have any transformative potential, and for whom. Did it disrupt received notions of doing research or provide resistance to authoritative regimes and encourage advocacy for research participants? My intention was not to transform participants but to use the stories for the purposes of theorising. However, participants in general commented on the positive cathartic impact of having told and read their stories. In my assessment this theoretical contribution is new and different from what exists in the literature and fulfils the intention to foreground the issues of importance in the lives of PWS within a broader personal-social-temporal frame.

However, the transformative potential for myself as researcher is something I can comment on more specifically. The project as a whole was a destabilising experience for me. My own traditional knowledge bases came under severe threat, and my sense of self was inevitably under scrutiny. I constantly had to interrogate who I was and how I came to be the way I am, the assumptions I held about the world, and how

research could be done. I understood better the fragility of what I know as “expert” and appreciate the powerful nature of professional knowledge. I had to do research differently from my “old” ways of knowing, and making this transition was difficult because the journey was fraught with uncertainty. I was often in the land of the unknown, and had it not been for the guided words of Lather (2001) “getting lost is okay and it’s a good thing too”, I might not have persisted. If I, (researcher-as-instrument) was changing and reflexive, then this impacted directly on the kind of theorising I could offer. I could see things in a different way. The “new” knowledge was unfamiliar even to me because it had been the first time I had engaged with such complex issues. What kind of knowledge is this? New knowledge? Good knowledge? Troubling knowledge? Beautiful knowledge? I revisit this issue again in Chapter Eight.

4.12 Summary Issues from this chapter

In this chapter I have explained how the study unfolded. Participants were invited to participate based on specific criteria guided by purposive, maximum variation sampling. Data were produced dialogically and shaped by a life history theoretical lens, intended to draw together the social, personal and temporal dimensions of the experience of stuttering and identity formations over time. The process of data analysis is iterative and influenced by the researcher's theoretical stance. Three levels of analysis, grounded in empirical data, contribute to theorising in the context of critical questions. The procedures taken to enhance the quality of the research process have been explained. In the chapters that follow, I present the three levels of analysis. In Chapter Five I present the research stories (first level analysis). In Chapter Six I present the cross-case analysis using all seven biographies while in Chapter Seven, abstractions and explanatory constructs are presented in response to critical questions raised in this study.

CHAPTER FIVE

RESEARCH STORIES

In this chapter I represent the data produced as research stories. Seven research stories constitute the first level analysis. The second and third levels of analysis follow in Chapters Six and Seven respectively. Each research story is a biographical account of an individual's experience of living with stuttering in his lifeworld over time. The research stories sit in conversation with each other and may be read in any order. I have chosen to present the research stories in two clusters. The first cluster of four research stories reflect the experiences of the participants who live successfully with stuttering while the second cluster of three stories record experiences of participants who continue to experience stuttering as problematic. The sequencing is also intended to illuminate the diversity of experiences across the participants.

The seven research stories are titled as follows:

Siyanda's story: Too Good to be True?

Kumari's story: Building Yourself Inside-out

Gareth's story: A Long journey

Sagren's story: Re-Inventing Yourself

Thabo's story: A Terrible Struggle

Hennie's story: Packaging and Presentation

Nontokozo's story: Little Hiccup, Big Problem

SIYANDA'S STORY

Too good to be true?

Our (Mis)fortune?

We came into this world with a stutter. I think Xolani my twin brother and I were born with it. It's God's will. Like everything else it is God's will. My mother was so happy with her little boys she never said anything bad about the stutter. It was just part of us. Our older brothers and sisters, six in all, never seemed to bother much about it. At home, the way we spoke, with our stutter, wasn't a problem. Outside home it was a different story. Our first bad memory of stuttering was in Standard One, my third year at school, when I was about eight years old. We went to school in Umlazi, an African township, in the 1970s and the rules were strict. One of the English teachers asks a question. If you don't know the answer then you stand up. He asks me a question. I am in the process of a stutter. I am trembling and I can't get it out. He hits me. He thinks I don't know the answer. A few seconds later I cough up the answer - out through my mouth and it drops into his ear. He shouts at me "Why didn't you say the answer when I asked you?" I tell him I was in the process of a stutter. He goes back and explains that to all the other teachers. I think he felt guilty. That is my first memory when I was punished for not answering a question on time because of the stutter. I broke the rules. The only other one who knew what was happening to me was my Xolani. We have this connection. We just sit quietly in class in silence. We are very scared that we might not be able to say the words.

The children at school pick on us because of the stutter. They tease us a lot. They knew if they irritate us enough then we will stutter. They say "Siyanda, you are in love with that lady. You have to date her". They are pointing to the ugliest one. They make me cross. I try to fight back and I stutter. That is what they are waiting for. They laugh. We play soccer and if you don't score a goal they say "You missed because you stutter. You can't kick the ball because the stutter goes to your leg, you miss". "You stutter because you are twins and your mother didn't kill one of you". In the Zulu community in which we lived there was a story about twins which started at some time in the days of the Zulu Kings of Dingaan or Shaka. As the story went it was a bad omen when twins were born and one would have to be killed. The people in the community had this belief that stuttering was a misfortune. They thought we were not

like normal children and they didn't understand what we went through. The adults didn't tease us but the children did.

I get so angry when they tease. I have to show them who I am. BoomBoomBoom. I fight. Xolani feels I am in trouble and he comes and joins the party. Boom! Boom! Boom! We have a good fight. That is only response we have to show that we are irritated. Angry! When we are so angry, we can't cough it up. The words wouldn't come out and they laugh more. We can't fight with our mouths. BOOM! BOOM! BOOM! we sort them out with our fists. We want them to know they must never mess with us. We have to show them what we are made of. We learned from our father that it was the way to sort out problems. It doesn't stop there. We are also in trouble at school for fighting. It was not good thing to fight and solve problems but we only learned that later on. My mother was the only one who supported us. She didn't think the stutter was a problem and she treated us as equals, like all the other children.

The stutter would appear at any moment, unexpected, out of the blue. I get the feeling of running out of air. Then the tongue is suddenly not in the right place to pronounce that vowel or consonant. The word is there in my mind but it just won't happen. There is a problem with that connection between the tongue and brain. I can't cough it up but the word is there. It is not that we are disorderly. You feel out of breath, just running out. I don't know how to explain it. It happened often when we spoke and everyone noticed there was something wrong with us.

At school, we became Shy Guys. We just keep to ourselves. We never told anyone, not even our mother about our troubles at that stage. The only thing we take part in is soccer. I was good. I played position six. When it is time for debates and speech contests we just say NO! We knew we were different and they will laugh. It was easier to keep out of things. We didn't have many friends but we had each other. We played with our cousins in a small group because we knew they wouldn't tease us. They also help to protect us, so if we fight they help us too. Because of the stutter we didn't expand the network. In the class it was just a matter of answering the question and sitting down. No more. We didn't want to even socialise with the others. We won't watch the movies or do anything else with the others because we didn't want to be exposed. We didn't want to be the centre of attraction. We just did our own thing and got up to mischief too. My mother says we were naughty and stubborn boys.

Primary School in Umlazi was harsh and we were caught in a vicious cycle with no words. You didn't do your work. Ten strokes. Come to school late. Twelve strokes. The punishment was too heavy. It was not just strict. It was unfair. The situation got bad. We were isolated, reserved and we were punished often. The trouble was not only because of the stutter. At home, we had a broken family. We go home and we see our parents fighting. My father used to beat my mother and we watch. Helpless. Speechless. We try to hug my mother and comfort her. It affects us physically, mentally and emotionally. The atmosphere at home is so tense. We don't do any homework and when we go to school and we get punished for that too. We are back in the class and we are so emotionally and mentally distracted that we are not in a position to do work.

This happened for about five years from Standard One and Standard Five. All this stuff put together had a negative impact. We couldn't speak our mind. We had to escape from school, from life. So we play truant and go to movies and play in the parks. Then the principal calls my mother. We are erased from the register. My grandmother takes us back and begs the principal "Please take them back. They have all these problems..." Then we get re-returned to school and the whole cycle starts again. Life is too hard. We are very silent and in pain. Eventually, we just drop out of school in standard five when we were about twelve years old.

One day, around that time we dropped out, we decided we had enough of my father's abuse. We stood up and fought back. We found our voices. We told him "We are sick and tired of this thing of yours and now we are in a position to fight back." We grab hold of him and with our hands around his neck we threatened him. That was the last day he hit my mother because he knew the kids had grown up and they meant business. He left, but he took everything with him. There was an empty house and no food. My mother, who worked as a domestic maid, had to find a new house and we went to live in Inanda, in the informal settlement, or as people say "the shacks". That was a very painful time. I don't even like to talk about it. For two years we lived with no money. We never knew when we would eat. We lost focus and stayed out of school for two years. It had a huge negative effect. The stutter was there and it was a problem with everything else. We were going on the wrong side of life. My mother wanted a better life for us and begged us to go back to school. She never said anything about the stutter but she said we need an education to succeed in life, to get out of this mess. We went back to school but only one of us made it through. My brother dropped out again in standard six.

Turning around

I continued in high school, alone, and still the Shy Guy. I still didn't want speak, be exposed and the centre of attraction. I carried on in this way until some small things happened which started to change my life around. I grew hungry for knowledge and then I became greedy. I read everything to know more. I was playing soccer and become team captain. I started to get good marks in my tests. The children didn't tease me. The current was starting to flow in the right again. The current was pushing me in a new direction. One day, when I was in Standard Seven I met Bheki on my way home. He was running a drama project and asked us to join. Maybe he thought it would help with stuttering. We said no. A few days later I was curious and watched from a distance. It looked good but this not for me. Bheki was persistent but I was resistant. I stutter. I can't do those things. He begged "Just try, just once." I tried just to show him I can't do it but he was very, very clever. He set up the audition very differently for me. I didn't have a script. It went something like this

Bheki: Laugh Siyanda

Siyanda: How can I? There is nothing to laugh about

Bheki: LAUGH

Siyanda: I can't

He slapped me a few times

Bheki: Now laugh

Siyanda: Laugh, laughter (tears rolling down my face)

Bheki: Cry

Siyanda: Cry, Cry (I cried)

Bheki: You did it. You have great potential

He didn't make me say words. I used emotions to communicate. I didn't speak or stutter. A really good audition for someone who stutters. He taught me some important things. I had potential. I can communicate. Communication is not just about words. I can communicate even if I stutter. It was a small step but a critical one, from darkness into light. Inside, I was a natural dramatist and maybe Bheki saw that. He saw more than the stutter. After that, I attended all the rehearsals and I started the first drama group at my school. I had a good new feeling in me. I soon became popular in school and started to enjoy it. I remember one girl saying to me "Siyanda, you are a leader". Maybe she was right. I gained confidence and represented my school at the Youth Development Sessions. As a member of the Youth Interaction

Group I went to many workshops and training courses. I learned so many new skills. The thing that helped me with the stutter was the stage techniques and assertiveness skills. These skills helped me to communicate better with an audience. I learned how to position myself, use gesture, facial expression, change the loudness and tone of my voice, speak slower, clearer, breath control. My stutter seemed less of a problem when I used these techniques. I could communicate better and I even took part in debates. The stutter is always there but I am moving away from the darkness of being the Shy Guy. Things went well at high school and I was in a position to communicate even with the stutter.

I feel confident so I start acting. Stuttering is disruptive especially when the character I am playing wasn't meant to stutter and the whole crowd is watching. I can't make it go away but I can make it easier by getting the airflow better. I had learned breath control as part of drama. I figured out that if I breathed a little air out and made a slight sound I could continue. I learned how to manage the breathstream to keep it flowing. I also worked out a way to use the stutter to my advantage. I integrated it into my stage technique. Sometimes, I pause for effect and emphasis but I am really in a stutter. I developed my own special style, Siyanda style. People don't think of it as a problem. The best part is that they really listen. When something is different it attracts attention. I can also use the techniques off stage if I choose but I generally focus on what I am saying and not the stutter and techniques. This is what I do on stage:

(Audible airflow) On the 21st I was with (I pause for effect when I stutter) my everlasting one, talking talking talking (I use repetition for effect) about our gift from God, being unaware that was the last day, being three is a crowd, being three is a crowd (I repeat the whole phrase for emphasis)

During this time I joined the Youth Interaction Group. I also learned more English so I can speak to people from the higher level, the English-speaking, educated people. Learning English was good for me because I was in a position to be involved now with people of other races. I also have the benefit of using two languages. It helps with the stutter. If I am stuck in one I use a word from the other language. Sometimes I change over just to make myself understood, not only manage the stutter. If I want to place myself in a position of greater power I can use English. I also stutter less in this language maybe because I am in a higher position or because I am careful about how I speak. I don't do this always because I don't want to be perceived as superior.

Down again

Things were going very well until I failed Matric¹, my final year at school. I was shocked and everyone was shocked. I can't explain it, not even now. I was demotivated and went to work. It wasn't what I wanted to do but I had to live and earn some money. I was a kind of supervisor in a tyre company for three years. I had the drama on the side but I was going off-track. I started drinking and I was being self-destructive. I wasn't happy in the job. I felt oppressed because we didn't have rights as workers. I was feeling trapped. None of this was good for me and my speech, it all goes together. The other guys at work were giving me a hard time because the boss put me in a superior position because I could read and speak English. Very few Black people at that time could speak and read English because we grew up segregated and spoke mainly Zulu. One day the workers assaulted me and I had a collarbone fracture. As I lay in the pool of blood I knew that it was a sign from my ancestors for me to change direction.

Living a challenge, rethinking me

I stayed in hospital for three weeks and I had a lot of time to think. I was black, poor, uneducated and stuttered. These were life's challenges but I was determined to live. I am a philosopher at heart and so I draw on the things I learn all the time to make my life better. You don't ask "How can I make the stutter better?" You ask "How can I make my life better?" Communication is in the centre of everything. You can't only change how you speak without changing who you are. What is my purpose on earth? We all were put here for some reason. What is my mission? After much thought and through the guidance of my ancestors I knew my mission was to be an educator and help to uplift the community. But I just failed Matric. FAIL. I remembered what that meant. First Action In Learning. I had to learn from my failure. I had to find alternative ways to achieve my mission. I was not formally educated but I could still be a teacher, a different kind of teacher. I needed a vehicle to live this dream. That is how I started my own Drama company. What I will tell you now is how I try to be a successful person, to achieve my mission. The stuttering story is wrapped up with it.

The first thing for me to deal with different kinds of discrimination and prejudice because of the colour of my skin and my stutter. As part of the Youth Interaction

¹ Matric: Final year of study in 12 year school education system in South Africa

Group I was always involved with different kinds of community and youth programmes. Michael, a white lecturer at the local university coordinated some programmes. Once he invited me to Royal Hotel, a fancy, high-class, five-star hotel in central Durban. This was still in apartheid times, in the late 1980s. The waitress was a white lady. She didn't like the idea of me, a Black, sitting on a beautiful chair usually occupied by Whites. She didn't want me to contaminate her. She put my plate at one end of the table and shoved it across the table to me. Everyone noticed and they were so cross. I didn't say anything. On another occasion, I was running a skills training group. Two White guys left the group because they couldn't entertain the idea of learning from a Black. It was their choice but it didn't feel right. It was a time when Black people were treated badly. I once played Eugene Terreblanche, *Die Wit Wolf*⁶, which tells you how Black people were treated. The words are in Afrikaans.

Kyk Hier! Swart hond! Kom hier! Kaffir! Die tafel is nie skoon nie... Ag Man, Ag Man! Hulle met krus hare kan niks doen nie, niks doen nie.

(Look here! Black dog. Come here Kaffir⁷. The table is not clean. Oh Man! Oh Man! They, with their curly hair cannot do anything. Nothing!).

In the transition from apartheid to democracy in the 1990s in South Africa I learnt to accept who I am and to understand myself differently. The concept of African Renaissance⁸ has given me the power to not look down upon myself. If I do my own thing which is different to yours then it does not mean I am uncivilised. We don't have to adopt the culture of another and try to avoid our own so we can be seen as "an educated somebody". The African Renaissance gives me the power to celebrate who I am. This includes my black skin, my African nose, and my stutter. I need to restore my pride in being human, to respect myself and to understand that we are all equal in the eyes of God. For me, now it is normal to stutter. It is part of me but it is different to you. Can we live with difference? Unity in diversity? There is also much of me that is just like you. We all do things differently. My stutter like my Black skin can

⁶ Wit Wolf : reference to Eugene Terreblanche, a member of the extreme right wing group ,Wit Wolwe in South Africa.

⁷ kaffir : derogatory term used to address Black people in SA (Maharaj, 2001).

⁸ African Renaissance: The term is intended to signal a new African world in which democracy, peace stability, sustainable development, better life for all, non-sexism, non-racism, equality among people and nations are valued. The task requires Africans to restore their dignity and pride and create new futures based on the goodwill of people. This occurs against a background of colonial oppression which, for centuries, impacted on the lives of Black people on the African continent and denied their humanity (Mbeki, 1998).

be viewed by many as an ugly thing. How do you change ugly things into things of beauty? That's the bottom line. What determines people's perceptions of you is how you present yourself, what you reflect of yourself. They can see you as you see yourself. I learned to reflect a positive image of myself with a stutter. We, as stuttering people, need to show that we are not less gifted. Stuttering is an addition to what God has granted you. That's my own teaching. We need to perceive it positively ourselves and reflect it positively.

I have grown a better feeling about myself over time and therefore I am able to pursue my mission through my stage work. My trip to America was a sign that I was getting somewhere. When I enter the stage it isn't the stutter I think of. I firstly cry because I am in the process of achieving my mission. I cry because I am doing what I love best. It's like saying "Okay, God. I am doing what you put me here for". When I do the drama it makes my heart and soul peaceful because I am doing what I love best. I get into a spiritual trance-like state and this also differs from the ordinary Siyanda. I am like of another world. It is indescribable. Then I get into character and become Dingaan or Eugene Terreblance. Most people would get very nervous. I have a different sense. I call it composure. It is more than confidence. It is about knowing that I am doing the right thing, educating my community. I have a powerful feeling and a driving force that makes me put my heart and soul into the performance. Then the words flow, stuttering technique included.

I don't have a prescribed way of how I will interact in any situation. I use all the resources I have and choose what is suitable. It depends on the situation. The thing I do is adjust to the level of the person I am talking to, not to the stutter. I don't pay attention to it. When I took my Drama group to America in 2000 I met so many people. I also met an African-America professor, who is the head of eight Universities. They really praise him there. When I met him I talked to him as my friend. I did not degrade him or myself but I adjusted to his level. I am speaking to a man of higher calibre so I must mind my language and courtesy. I am friendly in order to avoid the formality but I mind my language. I don't do anything about the stutter specifically. Siyanda is there so the stutter is there. It is a matter of believing in yourself. I believe that we are in this world like a puzzle. Each of us has a part in this partnership. When I meet the high calibre people I must believe strongly in myself. I must respect myself as an equal. I know it is okay because he is listening and shows that he wants to know more. I can pick up those cues. We find common ground

despite our differences. When the stutter pops up I just ignore it and continue. I don't get thrown by the stutter. The professor didn't too.

What others think? Just laugh it off

People in my community know I stutter but they also know my talents. They often ask me to speak at their functions. The other day I was called to speak on behalf of a clan at a pre-wedding ceremony. The stutter was there but it was no problem. Recently, I was running short of forty cents. There are times, even now, when I don't have any money. Anyway, I say to the lady at the stall "I am so hungry. I really need to eat this vetkoek⁹". The lady says "Okay, you can have it. I know you". "How do you know me?" I ask. "You stutter." I laughed. I don't get offended when people say that these days. They notice this difference and they are in a position to identify me. Now I know how to handle it. Another day I was speaking to Stanley Ngcobo. I phoned and he identified me immediately by my stutter. "I know you, it is you Siyanda. Are you still stammering? Why don't you get rid of this thing?" It was his way of joking. I just laughed. Laughter is a strong medicine. Not only I laughed. He also laughed. So I relieved him from his stress, I made him laugh. That's another way of looking at it. People notice the stutter but I don't see only a negative reaction. If they do laugh or mock it is their business. I just ignore them. After the performances at schools I talk to the children and take their questions. For most of those people who stutter that may be hard to do. I see it as the right thing to do, to help others. It makes my soul free to be contributing to a learning process and to my job as a teacher. I think I sometimes confuse the audience because when I was doing the character I did not stutter too much but when I speak to them I do. I simply speak and speak and speak. They don't seem to be attending to the stutter. I think they respect what I am doing because I help them to learn and to pass their exams.

There are times when there is a big display of stuttering when I am on the extreme ends of emotion. Very happy or very angry. The other day I came back expecting to find the cast there for the rehearsal. After rushing from the other end of town there was no one there. I was so angry. The only time I really struggle physically with my speech is when I am very angry. Then I just freeze. I can even smash a cup. It's part of being human. I let it all out. I scream and rant. I am angry and diffusing the anger. And the next thing I know I am shouting aloud and there are no words coming out. I

⁹ vetkoek : Sweet doughnut rolled in syrup.

am stuck. They just stare for a moment and then everyone bursts out laughing, me included. I have learned to come to my senses quickly. The anger subsides quickly as we sit down and analyse the problem and come out with some solutions.

To achieve my mission I must also be a leader and to be a leader I must be good at communication. Good communication does not mean just fluent speech. It means that you must read the people and situation well. I apply all my skills to communicate well and to keep the communication going. Let me take you to a board meeting:

On the board of my Drama Company there are people from all different professions. There are teachers, journalists and librarians and people from the community. I put my Director's hat on. I am in charge. We all sit around the table to discuss the agenda. I have prepared well. Knowledge is power. There are people from high-calibre backgrounds and grassroots. I have the skills to link up these different departments. I am the common mediating factor. I treat everyone with love and respect from high calibre to grassroots. We all have different potential and we see things from different angles. I listen to each one, to their inner thoughts and value their contributions. I know what it is like to be at grassroots. Prejudice and discrimination is really alive and kicking. The people from high level sometimes have this superiority complex. I don't know if that's what you call it. I listen to all sides and don't suppress people and their feelings and creativity. To keep the communication I must also be able mediate conflict.

I know the communication style and personality of each one. Phumzile is the ant. She works very hard and gets the job done with little fuss. I know I can rely on her. (I sense conflict). Mr. Khumalo, our financial secretary, is a bear. He is forceful protects his ideas. He can get very obstinate if things don't go his way. (I know the reasoning style of each). I can see that Sipwe is ready to attack. (I observe each one carefully). He is the fox who cannot be trusted but he has talent. If I sense tension or conflict I diffuse the situation immediately. The stutter is still there because Siyanda is there but no one seems to bother with it too much. I use the techniques if it very gets disruptive. By the end of the meeting we get the job done.

You must also learn constantly and deal with the troubles. As a Director I have learned about financial management, how to find the work, write the scripts, organise the cast, arrange transport, strategic marketing. All this knowledge puts you in a good position. I am mingling with people all the time. I am networking all the time, whether I am in the community or seeking donors outside. I don't feel shamed of who I am. I

just put on my best appearance with the stutter. Things don't always work out. The company is non-profit and I often don't have any money. I am willing to wait for the fruits of my labour. In the meantime I just persist. I feel demoralised sometimes. The other day we were stuck on the road after the taxi broke down after our last performance and we ran at a loss. I know those who will threaten my position and project and I keep away from them. I have been caught by hidden agendas before and I am careful now. My mother always helps me to see to see the bright side. I get up and go. You can't keep a good man down.

Things worked out differently for Xolani. He didn't do drama and I feel that he took the wrong path and went downhill. He got into trouble for stealing and even went to jail. Now he works but he is a one-word man because he stutters very badly. The only way we get into a conversation is by purposely picking a fight with each other. If he says something I will say the opposite. Then, there is the electricity going again. Otherwise he closes himself off. He doesn't make connections.

Acknowledging me... with my stutter

I really believe that our recent trip to America is a sign that I am getting somewhere. It was payback for all the investment I made for the thing I love. I am getting recognition for being Siyanda, the Director of my drama company. Now people in the community not only know me but they do respect me because our project went to America. It puts me on another level, makes them see a gap between me and them. Now they realise I am someone. That adds to making me feel that I have potential. Look at what was written about our trip to America by the Director of the Social Action Project in his project report. Michael, the lecturer, who knows me for a long time also wrote a reference for me. They see me more for who I am, not just a poor, black man with a stutter. That's what counts.

I am pleased for this opportunity to support this International Arts Education project directed by Mr. Siyanda Masondo ... At each venue the audience response was overwhelming. The drama group are futurists. Their association shows how the arts can play an integral role in the 21st century ...

Dr. Bryant, Psychology Department, Indiana University, USA, 25 November 2000

...As a high school pupil he was the founder member of the first non-racial youth forum created in the greater Durban Metropolitan Region, the Durban

Youth Interaction Committee (DYIC). DYIC sought to promote unity and understanding among the youth of historically divided communities during a critical stage in South Africa's development to democracy ... Siyanda quickly rose to a position of leadership in the organisation's executive MANCOM. His charismatic and dedicated style coupled with a sense of strong commitment to rebuilding South Africa saw him earn respect among his peers...He is never shy to use his personal talent. This talent over the years has matured into a serious dedication to youth development and empowerment His level of professionalism in the management of his drama company has been evident in the awarding of a small contract by the Government Communication Information System to produce an interactive drama of the Government's midterm report to the nation...Here is a young man who through his own efforts and relationship with others embodies a spirit of ambition, promise, caring ...

(Excerpts from personal reference (2001) from Michael Collins, university lecturer)

I have listened to myself telling you this story. It seems too good to be true, even to me. I have come a long way from a life of disadvantage. I strongly believe we create our lives. I use my own teachings and the teachings of others to continuously make my life and the life of my people better. Here are some gems I have collected over time which help to make me a better Someone.

We make a living by what we get but we make a life by what we give
(Winston Churchill)

Whatever the mind of a human being can conceive and believe the mind of a human being can achieve (Dr. Scott. A road less traveled)

People are like stained glass windows. They sparkle and shine when the sun is shining. But when the darkness falls their true beauty is revealed if there is light from within.

KUMARI'S STORY

Building yourself inside out

A consuming fear

I started talking very late, when I was four years old. Girls normally speak early but I didn't. There was a reason for this which only I know. My family wondered what was going wrong. They thought I might have a problem with my ears or tongue or brain. They were wrong. It was FEAR, a gruesome, monstrous, all-consuming fear that silenced me. I never spoke for four years. When I did, it came out ssssstuttering. Fear caused my stuttering. The fear was like venom, which spread quickly to every part of me, every crevice of my mind, body and spirit. A deep-seated ugly, emotional fear. I tried hard to shrug off but it still lurked in me, unrelenting. What caused this fear? The MAN of the house, my father.

At the time in the 1960's we lived in a close-knit, unsophisticated Indian farming community, in Marianridge, about 20 km outside of Durban. We seem like such a normal family but when my father's farm truck screeches to a halt in the late afternoon we become tortoises in shells. Children stop playing. Our laughter dies. Switch the music off. Straighten shoes. The air turns sour. Mother rearranges the mats, frantically rolls the last roti¹⁰. She puts on a happy mask just to pretend it is all okay. The rest is still to come. He hasn't started drinking... yet. He reaches for the bottle. I watch as it dribbles down the side of his mouth. Foul smell. Foul taste. Foul feeling. The ogre emerges. We know what is going to happen. I have been watching for three silent years. By the fourth year I try to speak but the fear catches the words in my throat. I am stuck.

I am not the only one who is terrified. Never let a pin drop because he hates noise. My four-year old brother drops the vase and it crashes loudly, an accident. It sets him off, he ignites and thrashes the innocent baby. A bomb detonates. Take cover. He loses Control. BANG, Smash. THRASH. No one is spared. Not even my mother but she never strikes back. Never. We are too terrified to fight back. He lies in a drunken stupor, paralytic. The archetype crystallises in my mind as a spectacle of cruelty. I go to bed, petrified. My sister goes to bed, engulfed by fear. My sweet baby brother

¹⁰ roti- Hindi word for hand-made bread

goes to bed, confused. My mother goes to bed, silently fearing tomorrow. I get out of bed, stuttering. My sister gets out of bed... WET. My brother gets out of bed... stuttering. My mother gets out of bed, dreading today. He has already left to work the farms but the atmosphere is still fogged with tension. It cultivates our bedwetting, stuttering and hatred.

My mother is in the kitchen, already making breakfast and life becomes bearable again. She has two spots on her face. One large red one on her forehead because she is a dutiful Hindu wife. The other is above her eye. Black. A grim reminder but still she serves him dutifully. She treats him like, God like all my aunts treat their husbands. If she didn't everyone would wonder what was wrong with her. But in a strange way she is also strong. She soothes our pain, shields us, and protects us. She tries to make life normal and liveable. We survive because of her love. She prays. She tells us to pray. I rebel. God! What GOD? Pray to who? For what? Why? Never. I lost faith. After eight years of hell, I had a lacerated spirit and life just oozed out of me. I was a HUGE empty void. He stopped drinking by my eighth birthday but nothing much changed for me. The damage was done. I put on my dark glasses and dragged through life.

School was a plain old Indian community farm school, nothing special. They knew me and my stutter and no one bothered or teased me. But I knew I was different. Had they made a big deal out of it, I would have been crushed. From the outside I appeared bubbly, talkative and friendly. The view through my lenses looked very different, very dark. Nothing was nice. I drifted on and put on a front. I remember every teacher. My class one teacher was a STRICT MAM and I did not like her, but at least she was a she. Rather a MAM than a SIR. Each year after that was a SIR SIR SIR. Mr. Ranjith, Mr. Singh, Mr. Naidoo. Powerful, male figures in my eyes who grew my fear and my stuttering even though they were nice to me. My stuttering became severe. I was just AFRAID. STUCKStuck. AFRAID. The only good thing was my best friend Rangini. We were well-suited to each other because we were quiet and we silently blended into the background, remaining unnoticed. I was quiet especially in the class because I didn't want them to notice there was something wrong with me.

Mother's advice

Although my mother never said anything about our stuttering to us she talked about other things. She desperately wanted us to get out of this hole. Mother's famous words were "You must live a better life. Every one must have careers like Uncle Bala's children. Find good-high paying jobs, like the White people and that goes for you girls too. Times are changing. Don't be like me. Earn money, buy houses, be progressive. I hope you girls are listening. You must find Nice Boys (rich boys, good boys, boys who didn't drink). Did you hear me? Nice boys. Like Uncle Bala's children. (Uncle Bala was her gold standard, a high-earning professional). Don't even think of leaving school like Uncle Gona's gang. What good did it do them? They are just sitting at home doing nothing. You must do something, become someone"

She didn't know that our stuttering was caused through fear, or did she? She knew that it wouldn't help us get a better life. She said nothing to us about stuttering because no one talked openly about such things in those days. She sent my brother and me to Speech and Drama for a whole year. It was the only place she knew of that could help us. In the 1970s and 1980s there were no speech therapists in Indian communities. I hated Speech and Drama. I couldn't speak properly and stuttered the whole way through. Miss Christopher made us do verbalacrobatics, which was not good for me. The other children were perfect and they were from the city. They spoke beautifully and shaped their mouths like White Miss Christopher. My stuttering looked even worse. Eventually, we left with our stutter.

Speech flows better

By the time I reach high school, the fear was entombed in me but I tried to suppress it. I experimented with my voice and discovered that I had an expressive, interesting and clear voice. When I used a special tone and casual manner of speaking I could speak fluently, not perfectly, but better. I used this special technique when I presented prepared speeches in class. I made minor adjustments to my speech which I can't even describe, to keep myself untangled. I learned the words off, by heart, as I stood in front of the class and spoke in an animated parrot-like manner, hiding stutter. Gradually, I began to use the minor adjustments more and more. I sounded fluent and normal and I got away without anyone noticing the stutter. I was still quietish but I learned to put up a polished exterior. The inside and outside of me were very different. Sometimes the stutter would slip out but I would squash it. All

the children who walked with me to school for six years in primary school never bothered with my stutter. The same children traveled on the bus to high school for six years. They still never bothered. This helped.

When I reached my final year at school, the speech flow was better, but the rest of me, inside, was still an empty hollow. I was detached, isolated and lonely. I had friends, but no best friends because Rangini went to another school. My self-esteem was low. Rockbottom. I was fashioned out of fear. I am too afraid to let ME out, too afraid to make mistakes, too afraid to say the wrong thing. Every one makes choices for me because I don't choose. I don't want to be wrong, I don't want to be judged, so I don't choose. We are at Salome's house, a warm loving home, with a caring family, so different to my own. They ask me what I would like to eat. I just say "Anything." My favourite, standard word. I must fit in, comply, blend into the background, be invisible. Nothing. I don't really matter. They give me cabbage and roti. I hate it but I eat it. Later on, Salome and I get ready to go to a party. My mum gives me all her savings. We try on dresses and I love the black one. It is my favourite colour but Salome says that the red one is prettier. Linda says the colour is too bright. Maggie, Sagrie, Rangini and Savi like the red one. I take it the red one. They must know better than me.

Escape the world and follow the pack

I battle with Real Life and so, while in high school, I frequently slipped away quietly into a dream-world, a Mills and Boon dream world. It was a wonderful world of love and romance. The maiden in despair, she cries and the charming prince comes riding in and rescues her. They get married and live happily ever after. I read every book I could lay my hands on. I decided that I must find my knight in shining armour to fill this desolate void. I was desperate to find a boyfriend so I wouldn't have to be lonely, fearful stuttering Kumari. I embarked on a new mission as I left high school, to find a Suitable Boy.

I went to university with my self-confidence at an all time low. I didn't even make a career choice for myself. I just followed the pack. I studied BA, like everyone else, although I did Commerce subjects at high school. If it is good for them it must be good for me. After a few classes in History and Psychology I knew this was not for me but I was too scared to tell them at home. I dragged through the year and missed lectures whenever I could. I used the time to find a Suitable Boy. There were lots of

nice Indian boys, University Boys, Hindu Boys, Rich Boys. I should find someone Nice. I perched on the wall between G block and the library every day. It was the highest traffic area where I perched as an ornament, all decorated, hoping to lose my invisibility. Nothing happened. Maybe it was because I still looked like a fearful stuttering girl. I gorged on negativity and I couldn't CONNECT with anyone. The void grew bigger.

I was forced to change my plans after the examination results arrived. I promised my parents I would try harder. I changed University and my course. On the social front I mastered the art of casual conversation, I mingled and, socialised. We weren't allowed to go out often but one day I went to a party with my friend, always hoping to find a Suitable Boy. Finally, I meet a Boy. The stutter is there but he can't see it. I make sure of that. Here's my chance. Let me check if he is a Suitable boy. I introduce a note of functional elegance into my speech to mask my stuttering and created an air of confidence, a muted flirtatiousness. I run through the questions in my head and he is a candidate. I must give him a chance. Old, single, stuttering females will have a hard time getting husbands. Me and the Suitable Boy Connected. Eventually he hears the stutter, he does not mind and life somehow seemed a bit nicer.

A (man's) world of work

I completed a new B. Com degree with distinctions and joined the world of work. The stutter and fear are both safely hidden. On the bus to Johannesburg I felt a sense of relief as I left home. At the interview, stuttering and fear jumped out. The Boss was an older man, an authority figure, White, Educated, Powerful. I tried desperately to keep it hidden. I flounder. It is Unrelenting. I stutter. NO! NO! I can't let this happen. They haven't noticed the stutter. Yet. I act quickly and desperately to put on a disguise. I use my special tone of voice, deliberate emphasis, confident façade and I sound beautiful. They give me the job. I settled in well and enjoyed the job. I communicated well with everyone. They noticed I stutter but it is so mild that it is hardly troublesome. The only problem arose when I had to talk to the Boss and luckily that was seldom. Even if I had a small, simple request like leaving a few minutes early, I set my self up for failure. I feel his imposing presence. I am a child again, terrified. He hollers in my mind. I know he is going to say No, No, NO. I stutter, radiate negativity and do not make a convincing case. I lose all my conversational

grace, delicate pace and flowing speech. I am a blubbing child making an unreasonable request. He says NO. Yet, I know that he is a fair and sensible man.

Soon after, I found another higher paying job, still as a clerk. This time the Boss was female and I sailed through the interview. I stuttered a bit but I felt comfortable because she was kind, and caring. I really enjoyed the job. I did well at work but never applied for promotions. I dreamed of climbing the corporate ladder. The dream dies as I pass the boardroom. Every seat is occupied by Men, Older White Men. The fear envelopes me when I hear their deep, booming voices. I explode my dream. I will never make it up that ladder.

Happily ever after?

My father died and I never mourned. Certain movements of the heart were no longer possible then. Life began to change rapidly as I smelled its multifarious odours. I left my job in Johannesburg to return to be married after a good two years of courtship with Dean. What does the book say? What happens after they marry? Live happily ever after? Sweet blossoms and roses. I was in for a rude awakening. In one year I became a dutiful wife, daughter-in-law, student, new employee, and mother. I cooked, cleaned, washed scrubbed, fed, studied and went to work. I reeked of domesticity while my husband lounged around and went out with friends. One day he kept me waiting at work while he hung out with the boys. I was livid, said nothing and pretended everything was okay, just like my mother. To complicate matters my father-in law lived with us. He drank and the sour smell of alcohol brought back my terrible memories. He was very quiet but I could not even sit in the room alone with him or bring myself to have a conversation with him. The fear stirred deep inside. So much for sweet smells of happiness.

I needed a job in Durban and this time the odds were really stacked against me. Besides having to deal with another male authority figure, I also lied about two things that could disadvantage me. My stutter, and that I was pregnant. I lied because the Boss made it clear that pregnancy was a sign of disloyalty to the company and I knew no one wanted an employee who stuttered. I settled into the new job and tried to hide the pregnancy and my stutter but both were eventually discovered and I tried extra-hard to compensate. I worked until the last hour on 28 November and Divesh was born on 29 November 1989. He was a beautiful bundle and I wanted him to be everything I was not. The euphoria of being a new mother dissipated quickly as life's

agenda grew more demanding. I couldn't be the loving caring mother you read about in the books. Sleepless nights, fevers, teething problems, a demanding work environment left me exhausted and even more empty than ever.

Stuttering ...all over again

He was two and a half years when he began to stutter. I know all about genetic theories of stuttering but I am convinced that the environment I created had more to do with his stutter than just his genetic makeup. Actually they are interlinked. I recreated the same environment I grew up in, although not as severe, and caused his stutter. Stuttering is like cancer. I don't believe it is hereditary in a traditional way. I believe that whatever you live, your thoughts, fears and superstitions, you carry through into the next generation. You create stuttering because you have created the environment and responses that support its creation. I think you may even carry that creation, the negativity, at a cellular level. How this happens has always been a source of fascination.

I was devastated as I watched Divesh very closely. He struggles to speak and the words just don't come out. I panic, scold and feel every block. He does not know he stutters but I do, and I hope and pray it will go away. I try to speak gently, give him praise, read to him, cuddle him but he still stutters and soon everyone notices. Dean is not concerned. He says "You do well with your speech and you hardly have a problem" (if only he knew). He will grow out of it. (Grow out of it! I haven't in 30 years). Divesh talks a lot. SLOW DOWN. SLOW DOWN. I tell him. He whispers and laughs. He is a joy but he is stuck. I don't want him to stutter. I want him to be normal, confident, fluent and perfect. I put conditions on loving him. I knew that was unfair but I don't know what to do. Society is so critical of those who stutter and I don't want his stutter to spoil his dreams. I rush him off to therapy at the University clinic hoping that they have found a miracle cure. They assess him and confirm that he stutters. They give me guidelines about interaction, tell me how to help him be fluent, to monitor fluency patterns. They explain that it is not my fault but I don't believe them. I try to follow the guidelines. It helps when I am relaxed and take time to speak slowly and play. I do a lot of this but I can't do it all the time. It takes lot of effort to do these things even though they seem so simple.□□² That was a block. It doesn't appear often but is noticeable. Anyway, Divesh continued to stutter. The

² Symbol denoting stutter (block)

more I try to get rid of it, the more resistant it became. I get impatient. I want him to get out of the block, like I do. He can't. I repeatedly tell him to slow down but I am really saying Hurry UP because he takes so long to speak. Dean just ignores it and plays with him like nothing is wrong.

Things were worse outside home. We go to a family prayer and by now Divesh is three and such a chatterbox with an exuberant personality. Everyone can hear him stuttering and I hear it loudest. He tells them all about the dinosaurs. He knows all their names.

Pttteradactals lived...

Block Block T-rex is the largest ...

They are Block, block block

I hear the stutter. No one says anything. I can't bear it.

I am so embarrassed and I say. Don't mind his stutter. He speaks that way when he is excited. (He actually speaks that way most times).

I tell him: Say Jack and Jill. (I know that he won't stutter then).

Finally he breaks out: Jack and Jill

What relief! (You never stutter with songs or rhymes)

I promise to buy him sweets if he does not stutter the next time.

I pursue with therapy for seven years, on and off. On when he is bad. On when I feel bad. On as he settles into each new year. On after each holiday. Off during holidays. Off during the cricket season. Off during trips overseas. Divesh learns skills which help him to be fluent. We practise, but not enough. Ten minutes each day is a long time. We tried different combinations. On-line management. Easy onsets, Breathstream control. Blending. He was able to use these skills perfectly and could be 100% fluent until his exuberant personality took over. We tried so many things to remind him. Notes, stars, stickers, praise. Nothing works for long. He is robust, talkative and HE STUTTERS. Lots of stutter. I fixate on the stutter when he is telling a story, yelling at his friend, taking charge of a game, ordering an ice-cream, answering the telephone. Stutter, Stutter, Stutter. He never stops talking. It even starts to get to Dean too and says: You are taking too long. Cut the story short." Divesh just can't. He has such a lot to say. It is tiresome living with stuttering.

Divesh's school reports were excellent. The report reads something like this:

Divesh is an excellent reader. Divesh has excellent leadership skills. He is sociable. He participates in all activities and often speaks in assembly. He is a pleasure to teach. He is an avid reader and likes challenging work. His stutters affects his oral presentations. However, this does not hinder his ability to perform in any activity.

I had long conversations with the therapist and she talked about accepting stuttering. I couldn't relate to what she was saying because the void in me was still there and I was spiritually empty. She does not know my story. I mention bits but not enough. I can't help myself. I can't help him. I realised that it was me I had to deal with. Eventually we stopped going to therapy.

A gradual reawakening

Divesh was about six when I started reawakening, very, very gradually. Dean started the spiritual journey when he lost a dear friend. He read about matters of the heart, mind and spirit. Then my sister married Sagie, who is disabled – no, physically-challenged. He is an educator in every way and he opened my eyes and my heart. I started to peep at the world differently. I joined the Sai Movement, an international movement which teaches about human values. I was drawn to their sweet singing and their teachings about human values, peace, trust, spiritual development. We started our yearly pilgrimage to the ashram in India, which I hated at first because I did not have worldly comforts. Slowly, very slowly I began to evolve, imperceptible shifts like the hands on the clock, but shifts nevertheless. I start to question what is important for me. I start to look at myself on the inside and I did not like the empty spaces. Spiritual growth is not easy I still exuded negativity. We also introduced Divesh to teachings of human values of honesty, truth, justice to help him deal with life.

Dean as my spiritual partner, guided me through a difficult journey. He read books and made sense of them but I still found them abstract until I attended Mind Power, a self-development workshop. After four weeks of Mind Power I started to see a new me. It gave me the tools to concretise and operationalise what I had been learning about spiritually. It all started to make sense to me in a practical way and I could apply the skills to all aspects of my life. The basic concepts are about the mind and how you have the power to create who and what you want to be. You must be prepared to replace old beliefs with new ones. I learned to replace negative with

positive, to replace my lenses and see the world more differently and more brightly. All my life I used my dark inner world to construct every experience. Stuttering and fear were very much part of that dark inner world. I had to build myself inside-out. I understood that I created my world by virtue of the choices I made each moment. I chose to stop Divesh speaking when he stuttered. I chose to interrupt him and tell him to slow down. Importantly, I can choose differently. The six laws of the mind allowed me to understand my mind as something I can influence and change. The Law of Attraction states that thoughts that are thought with emotion become magnetised and attract similar and like thoughts. I have negative thoughts, which attracted negativity about everything, including my speech. If I have a negative thought now I knew the four steps to follow.

I think about changing a job. I am scared of the Boss. I can't speak well. He says I am not competent enough. Negative thoughts.

Step One: I explode the thought Immediately. I do not allow it to continue.

Step Two: Replace negative thought with a positive thought. I am working confidently. I do the job well.

Step Three: Exaggerate it into ridiculousness. I imagine myself scared and hiding under the table.

Step Four: Counteract it with its exact opposite. I imagine my fat male Boss hiding from me. Now he is under the table. Stuck.

I learned that the negatives only have power over me if I react to them. I worked hard. I did the exercises everyday without fail. In one such exercise we had to write 20 things you like about yourself each day. For the first day I couldn't get beyond five. I didn't know myself. I didn't like myself. I gradually got to view many positive things about myself. Mind Power became a habit and my new way of living. I learned to trust my logic and intuition and began to recreate myself to become who I want to be. I realised that I am unique and part of my uniqueness is that I stutter. Stuttering contributed to making me unique and to making Divesh unique. I understand and accept that we stutter and began to attach less importance to it. It was a kind of Letting Go of the hold it had over us but there was always the troubling reality of the world which still thinks of stuttering as abnormal.

A week after I completed the Mind Power programme, I resigned from my job. I fashioned a new successful Me, a more powerful, businesswoman; a more peaceful,

spiritual Me. I wanted to be my own Boss and create my future. I did and I have thrived. Divesh has also benefited from Mind Power because we have laid off him. I don't draw attention to his stuttering and I let him be him, with a stutter. He has excelled academically, and won a bursary at his school and is still as boisterous as ever but the social reality of stuttering never escapes us. Recently, he was asked to tell a story to a group at Bal Vikas, a human values class for children, where he has always spoken freely. For the first time he got into a block and refused to speak. It still hurt me a lot. Through Mind Power we have the tools to deal with these difficult situations but they still feel bad because we are different from everyone else.

Although Mind Power made a huge difference to who I have become, I still feel there is more I have to learn on this journey through life and so I keep reading to understand who I am, my stutter and about my purpose in life. I have become intrigued with the mind-body-spirit links. I was always curious about how one's fear, an emotion, becomes part of your biology i.e. how your biography becomes your biology. I was recently so excited when I read about The Journey, a book by Brandon Bays. Now I understand the issues of the other-than-conscious mind, and how the fear can be programmed into your cells at a cellular level to create stuttering. My stuttering was created from those early fears that left me so empty and depleted. I had to face those fears and forgive because it is the only way I can unleash my potential spiritual energy that has been blocked preventing me from being who I want to be. Divesh and I have both been on the Journey process and it has worked wonders. Divesh hardly stutters anymore. During the process they uncovered a fear he had about being abandoned as a child at eighteen months. With understanding and forgiveness, he is now a different child. He hardly stutters. I know that there is a spiritual source of infinite wisdom that we all have as children, which can be destroyed. We need to tap into that source. Although the process helped me to understand and deal with some of my fears, I still have deep-seated fears I must deal with.

Now I have come to new understandings about everything including stuttering. I have also been influenced by reading of a book, Conversations with God. I don't blame my father for everything that happened. It was my Karma. He was there to create a situation for me to become someone else. Philosophers say we are all specs of God but we don't know that. Through our lives and our troubles our purpose is to discover our divinity. Our sole purpose on earth is divine, it is to discover who we are. My journey continues.

GARETH'S STORY

A long journey

A sensitive little chap

These days nobody believes me, a 65 year-old grey fellow, when I say I stutter. But I have always been a stutterer. I do have the occasional block twice a year or so but as I have said many times, stuttering is really a non-issue now. Back then in the 1930's, it was a different story. I started when I was young, around three or four years old. I was a very sensitive little chap and remember my parents worrying about my speech. I suspect it was bad from early on. They said the usual fatherly and motherly thing like "Slow down, take your time". I was aware of the stuttering at that stage but I don't think I was too troubled by it. As a child I had lots of friends and we played hockey, cricket, soccer. We took our food down to the great Standard Ground, the famous cricket ground in Pietermaritzburg, and ate there. It was a real joy and down there I was never troubled by stuttering. I never felt I was being picked on or laughed at. Maybe I didn't even stutter much with them.

At home, in a pristine White Pietermaritzburg, life was pretty normal, good, most times. I am not sure that the Indians on the other end of town would have said the same. Times were still tough economically in South Africa after the Great Depression, but we were fortunate that my father had a good job and we could afford to live comfortably. However, on some occasions there were these verbal collisions at home. My parents, both of staid English backgrounds, were a difficult match. They had a love-hate relationship. My father was firm and dogmatic and my mother was quite spirited. So, a degree of collision took place. Verbal collisions and explosions! When these rows were on, for me, a sensitive little boy, it was like the end of the world. I don't know how it was for my older brother Neville. Those collisions made more of an impact on me then, than did my faulting speech. I wonder if that had anything to do with my stuttering? I don't know, but it was scary. Outside these moments my parents were caring, though it was not quite an outward display of emotion. I am very much like that too. Maybe the stutter is a family thing. My father didn't stutter but his speech was also disfluent and my brother is a bit jumpy but not anything like me. Nobody ever talked or ever discussed stuttering with me. Everyone

pretended it wasn't there. It may have been fine then because it was just how people coped, but in retrospect, maybe that wasn't such a good thing.

I started Primary School way back in 1943 at Merchiston Preparatory School, still a sensitive and very little four and half year-old boy with a stutter. I was a year younger than the rest. My parents set great store on academic achievement and making something of your life. I was trying to keep up on all fronts and I took things very seriously, perhaps more seriously than I should have. Early on in primary school I became very conscientious. I was bright, but not wildly bright and I worked really hard to do well. I did very well academically. The stutter was still bad, although not so bad that I could get a word out the door. I was never beyond making myself understood with my little friends. In the classroom, I did get away with it. Back then, the 1930s and 40s, it was an era of "children should be seen, not heard," different from the verbalising done in classrooms today. We didn't have to speak much in class and perhaps that saved the day. However, there were a few teachers who were aware of the problem and did understand, like Miss Russell, who cooked the books so that I could spend another year in her class. She was trying to protect me and soften the blow. I thrived academically. We used to do fortnightly orders: tests every two weeks. The names of the top pupils were called out in assembly. I was usually in the top three in the class. We all line up in assembly. Then the principal calls the names: Master Gareth Blake Second, Master Gareth Blake First position, Master Gareth Blake Third Position. I receive awards regularly, beaming with pride.

Never got away with it...

At home, stuttering wasn't swept away under the carpet totally. My mother did oral reading with me in an attempt to help but I wasn't able to read the essays back fluently. I tried but the words just wouldn't come out right. After a while they decided to try another option. We were never a wildly religious family but I went to the Anglican Sunday school. One Sunday we went a different route and I was installed at the Christian Science Sunday School. Christian scientists believe that problems were all mind over matter and that illness isn't really illness and that sort of thing. My parents thought it might help with the stutter. All I remember was that we sat around and each one had a turn to read aloud. Round robin reading. For me it was round robin stuttering and it just made it worse.

At school I never got away with it altogether. The stutter was there and growing. I wanted to forget about it and be like everyone else or better than everyone else. I must sound so pompous but I was always competitive. But they wouldn't let you forget. We hear the dreaded footsteps marching down the corridor. They are two classes away, one class away, and then they are here. The threesome, the principal, the nurse and the school inspector. Society watchdogs! We knew what they were looking for, all the misfits, all the problems. Maybe they would forget about me. Then they start: Come to the front when we call your name and problem: McDonald and Hastings - Headlice, Smith - Can't See Well, Lovemore - Cripple, Blake - Stutterer. I just want to disappear into the ground. Is this all they know about me? Hey, remember I came second. They fill out the forms. I remain silent. Powerless. They make it unbearable. Everyone knows I am a stutterer but this is a painful public display. They didn't organise any help, but this just helped to grow the problem. When you are young the last thing you want anyone to say is that you are different or you have a problem.

Soccer Boss and all things nice

Fortunately, there was always the other side and I gave as good as I got. Playground and friends were a real joy. I had a talent and passion for soccer. We get to the field, in teams. Captain. Gareth Blake. Coach. Gareth Blake. Manager. Gareth Blake. I am the team. They played in My team. I hand out the carefully painted badges. I select the team, coach them, talk about the game plan and we play ball. We run, shout, kick and scream. Stuttering is furthest from my mind. After the game we talk about the game, the best kicks and missed goals. There is no trace or mention of stuttering. I race home with my bicycle-friends and then join my cricket-friends, lots of friends. No stuttering issues. Somehow I don't think it was much of a problem with them. I had so many friends and that was important because I was always part of the group. The only friend the stutter was different with was my best friend Edward. I always stutter with Edward even up to this day. It is really unusual. I try to make sense of it. Maybe it is because he was always erudite and eloquent. He had all the social graces and next to him I was the stumblebum. Edward and I spent much time together and he enjoyed art and together we spent hours drawing and I discovered another talent. I displayed my drawings. They spoke for themselves and I was so proud.

Bigger demands, bigger blocks

My secondary schooling began in the 1940s at the noble Maritzburg College. Those years brought on a new set of challenges and along the way the stuttering grew. The school was a pseudo-private, all-white, very English school with fancy buildings, fancy traditions, hats and black blazers, even in the middle of the sweltering Pietermaritzburg heat. It was certainly no ordinary public school. The competition was very aggressive. I made the A-class but was still very young compared to my hairy, rugged rugby-playing counterparts. I couldn't get away with the stutter as much because we were expected to speak more in the classroom. Luckily for me, it was not excessive verbalising. The stuttering was getting worse because I could feel feelings better. The negative feelings accumulated and so the stutter grew. The demands for oral work in class were getting greater as the blocks were getting bigger and longer. My silences grew and they filled up with anger, frustration, and embarrassment. Everyone knew I stuttered but no-one teased me to my face. It was not polite to say anything about it, so we all pretended it wasn't there.

The academic pressure increased as we were expected to take public exams in three grades - standard six, standard eight and matric, my final year at school. There was always the pressure to do well. My mother knew that I was really edgy at exam time. She put ten drops of phosphorine in water, her own special muti (medicine) which I swallowed. It had a calming effect and was meant to help the stutter too, which grew worse during these times of great stress. But there are moments I will never forget. On one fateful day in the Latin class and we are translating various prose from the story of Hercules or Ulysses. The lady in the story is Prosephine. It is my turn to speak, to recite the prose. I recite nervously trying every trick to keep the unruly stutter under control. My nervousness was quite obvious in my speech. Amidst the struggle to keep my speech going, I called Lady Prosephine, Lady Phosphorine. I felt absolutely stupid and there was nothing I could do about it. My speech was really stupid to the whole class, the teacher and me. Of course no one laughed openly then but I can laugh about it now.

Another moment I recall is also about Latin but this time about the teacher who understood my predicament and protected me. I had been feeling extremely embarrassed about the stutter and I once said to him "Sir, would it be awful if I didn't do these verbal things?" To which he replied in a general statement to everyone in class "No one needs to do things they don't want to". I remember those words as

clear as day. I think sometimes it is better not to confront and fail hopelessly, to expose yourself as different and put yourself through absolute purgatory. The environment was fiercely competitive and didn't prepare one to accommodate failure very well. You have to protect yourself sometimes. Stuttering was a big part of my life by this stage. It occupied great spaces even if I didn't want to admit it.

Not derailed completely

Fortunately, stuttering didn't derail me altogether. I maintained a competitive spirit and conscientious work attitude. I used to get all the work done and perhaps better than everyone else. My biggest frustration was not being able to show it off verbally by answering questions in the class. I felt I could do far better than anyone if I wanted to, (obviously I couldn't always) but there was always the fear that the stuttering would not let me show my real worth. Luckily for me most things were still written and I was able to show off my talent. So throughout high school I sadly-happily participated minimally in discussions. The reason I don't think all of this had a devastating impact on me was that I had many things going on outside of this. I was still playing soccer outside of school, which had a rugby-playing tradition. I played for a semi-professional team and did extremely well. This bolstered my image of myself. Added to this was that I still pursued my passion for art and developed this talent in my own time. I have a great flair for art which lasts to this day. It has brought me great personal joy. Edward and I would spend hours drawing. I was especially happy because I could do so well what others couldn't do. I still had all my friends, school friends, neighbourhood friends and with them I had little trouble speaking.

Relax, Relax but no Miracles

As I passed through high school my parents were still very concerned about my stutter which was relentless and they arranged for me to attend speech therapy. I drag myself to the top of the Natal Provincial Administration Building very unhappy with the arrangement. I meet Miss Norrie, a very nice lady who really wants to help me. I remember her very well. It is the era of relaxation therapy. I lie down and we start the progressive relaxation exercises, from head to toe. Clench the muscles and release. There are no other methods or speech techniques. She is pleased as I relax and am able to speak fluently as I prepare to leave. She watches from the top of the building as I mount my bicycle looking very relaxed. In a jiffy the bustle of life returns and the stutter is back with me. I can't apply the relaxation techniques because I am

a jumpy sort of guy. I use all the tricks I know depending how serious the block is, the seriousness of the situation and who I am talking to. □ Oh! There! That was a bit of a block which you probably missed. On occasion I even try to speak louder than usual, almost shouting to keep fluent, but I feel quite stupid. I continue with the therapy but complain bitterly to my parents. I hate it because it takes me away from all the things I really love to do. Eventually I leave. I would really like to track Miss Norrie down now. She would never believe how I finally turned out.

My father was vigilant about any help he could garner to get rid of my stutter. On the scene arrived William Kerr, the Miracle Man. Several newspaper articles appeared in the local Sunday newspapers in 1952 when I was sixteen years old and in my final year of school. Excerpts of articles in the local newspaper Sunday Tribune, 20 August 1952 reads as follows:

Among the 12 people being treated in Durban for stammering by Mr. William C. Kerr is a six year old boy, and two people aged 72. Mr. Kerr who has been treating stammerers in South Africa for the last few months says that he has found the cause of stammering and has an unfailing cure...

Mr. Kerr told me that he has never treated a group as large as twelve. He was finding it a strain because each stammerer was an individual problem and needed individual attention... In a weeks time he leaves for Johannesburg where another group of stammers await him and on the 8 May he sails for his home in New Jersey. He will return to the Union in September for a longer stay and will visit Durban, Johannesburg and Cape Town....The Sunday Tribune has been inundated with calls

My father, infused with hope, immediately wrote to William Kerr. In his letter he describes his concerns. I wrote the beginning bit:

Up to about ten years of age I had a pure uniform stammer. As I grew older I found that certain things helped such as draining my lungs of air before speaking. I recently found that swallowing just before speaking helps; but often fails to help me start. Then again I have been saying "yes" before commencing a sentence. I have found that this method helps in that once I have started properly, I gain confidence and the rest follows naturally. At times I am faced with a word which seems impossible to pronounce while

conversely at times too I experience no difficulty in speaking without a stammer.

My father wrote:

In amplification of the foregoing I have personally noticed that there is no trace of a stammer in his speech while playing sport or when he is excited about any particular subject – in other words, to a layman, it seems that if he has no opportunity of thinking about his impediment before speaking he appears to have little difficulty in speaking.

The miracle was not to be. I never met William Kerr.

Words and pictures please

I began University at age 16, pimply-faced, no hair on my legs, and shedding most of my friends for a brand new experience. My father chose our careers. He chose architecture for me having carefully examined all my marks, teacher's remarks and that sort of thing. It was a good choice because it brought together my analytic Maths side and my creative art side. I settled in and made new friends. I was not so bad at speaking and I got by okay with my friends. On some occasions, especially in the studio, they had the misfortune to see me stutter when I tried to explain the drawing on the wall.

Communication is a very important part of architecture and you must convey feelings in your presentations - like the feeling when you move into a huge cathedral and there you are standing, this tiny person in this great big space. You need to capture the feeling of when you climb into an attic, its' wood all around you, there's an eiderdown and its freezing outside. I would try to capture all this on paper with my drawings and that's where my drawing talent did help. However, as much as I would be able to carry feeling through in my drawing I would still need the words to add the final touches and I just couldn't do it. The pictures did a far greater job than my feeble stuttering. What really irked me was that there were these verbal sorts who never really did their work. They would have hardly anything on paper. But they could talk and get away with it. It made me really cross. I was very suspicious of these verbal sorts and their wonderful words.

I had to contend with portfolio examinations. You go into the room with this big folder under your arm and the heavies are inside. They call You, one at a time. They open your folder and they examine it. I put all my talent on paper, with drawings. They ask "What made you do this?" I can't talk to enhance the presentation. I worry that the stutter might disadvantage my marks a slight bit but I add my bit with a struggle. I know my subject well but in this instance, they know it better but I manage to get by with outstanding results.

Never an easy ride

At the end of each term my parents would arrive in the great big Chev to pick me up. There is one ride I would never forget. There are some events that stay with you. I drive the car all the way to Pietermaritzburg and I am excited and bubbling over. I want to tell them about my wonderful results, the soccer matches, friends. The words just wouldn't get out. I stumbled and it came out all wrong. Words – struggles - half said-words, half-heard. Words coming out and then gulped back-way-way-down. I try to push them up all over again, I just can't. Angry, frustrated and exhausted, I reach Maritzburg. What a mess! My parents still never said a word. No one really understood my 80 kilometres of suffering.

It is quite difficult to explain what really happens at the moment you stutter. It's never really just a moment. It is a before, during, after sequence with a long history and many memories. It's the funniest thing because you will never know until it's upon you. Ohmygoodness! There's a block. I didn't know the block was coming. I had no idea. It's so absolutely involuntary. I also think that it is precipitated.

Let me explain to you like this. Imagine you are water skiing.

They get going with this boat and you say

"Okay. I am ready" and up you'd go.

You'd get up and think it was fantastic.

Then in your little head something would say " No! You can fall off this thing pretty easily."

BUMP! You would fall and the block happens.

It happens in the moment when the possibility arises that you go down.

It's those negative thoughts.

The humiliation is what you suffer because you look stupid, a halfwit. Then, you have to pick up the pieces. The whole thing is just so embarrassing. I am not so sure always what people think but I don't want to embarrass them either. Nobody likes the

spectacle. It is also a devil of a job to get up again. It is really because you have damaged your image for a start. How do you do it? I just don't know. It is such a struggle to get up and go only to know that it will happen all over again. It doesn't happen exactly the same way every time. It depends on who's watching, whether it is a high stakes event and whether you are in the waters you know well. Eventually you do get up and go. If you don't, it is equally bad.

Stuttering is puzzling. I have often tried to make sense of it. The biggest thing about it is that you come across as ODD. You can't help but feel that you are not making a good image on this person you are trying to impress. If you are blocking and grimacing and twisting you don't feel like you are looking good. It is like being spastic and it is embarrassing to the audience. Only those with hard stomachs can watch a stutterer go through the motions for two or three minutes. The problem happens especially when you meet someone for the first time and you want to impress them. They would probably say, "Whew! That fellow really stutters. It is so hard to talk with him. Difficult! Difficult! Have I got the head for this the next time?"

Anyway, back to university years. My conscientious nature remained through University. It is part of me. I did extremely well at University. I don't want to sound pompous and arrogant but here is a CV I prepared soon after University. It provides details of my academic achievement and records some of my story of stuttering. I prepared it for a bursary application. It confirms and adds to what I have said already.

At an earlier age than average I began my schooling with the handicap of a stammer and I have been afflicted to a varying degree ever since. For those who have not experienced any form of physical disability it is no doubt difficult to imagine the psychological effects one suffers or the emotions one experiences. Spoken words have always involved more to me than most. Trends of thought often become obscured through the attention necessary for the utterance or single word. I do not intend elaborating on the subject, other than to state that, in my case, I have treated it more as a challenge and with this motive added to that of being determined to prove worthy of my parents efforts on my behalf, I have developed a reasonable degree of conscientiousness...

The choice of a course of study proved relatively easy. Architecture, a compromise between the arts and sciences, was a logical choice - a choice I

have never regretted. My first year was spent adapting to University life. In my second year I was more successful and received the Natal Provincial Institute prize for the best student of the year. I was also playing soccer for the University of Natal. The first half of the fourth year of study is devoted to six months of practical experience. It was during this time that I realised the importance of fluent speech to an architect. My speech, although for long spells being perfect, was highly suspect and had the embarrassing knack of failing me at some critical moment. It was then that I resolved that I could not express myself satisfactorily in words and I would have to express myself in some other form. I had always been rather better than average at sketching and painting... Which enabled me to sell concepts on an architectural scheme more profitably with the aid of sketches than could have been done by others with glib, smooth tongues. However, with the elimination of the importance of speech in my job, my stammering was becoming less – a standard which it has maintained, though fluctuating from time to time, depending on the mental stress prevailing. I continued to play and enjoy sport... I started my fifth and final year with a supremely confident air as I had not failed a single subject in my university career. I developed a more carefree approach which expressed itself in my designs. I turned out what I consider to be the highest standard of work of my University career. .

Time for Change

I was pleased with myself and my achievements at University and then it was the world of work. I was a young professional but the stutter didn't quite fit into the image of a swish professional. Speech that makes you sound like a half-wit does not make you sound professional and knowledgeable. There wasn't much work in South Africa for architects back then. I thought "Let's make a change" so I went to work in Rhodesia (now Zimbabwe) for a while around 1956. My brother was up there. Things did change for me there. I started reading the Rand Daily Mail, a South African newspaper. When I learned of the racial injustices and prejudices in South Africa and Zimbabwe, I sat up. My goodness! What is going on? I am not sure why I was drawn to this discourse but my eyes were opened. There was protest in Rhodesia which had something to do with the policy of selective franchise. I felt so strongly about the matters of the day that I felt I had to do something. Together with a friend, I canvassed door-to-door, with my stutter. We did our bit, or at least we tried. I don't know if it had any impact. I believe the right thing always prevails and no stutter was

going to stop me from saying my piece. Up until then I lived cloistered in South Africa, in an all-white cocoon. I began to understand the world differently.

I also started working in a small architectural practice in Bulawayo, a smallish town in those days. As a young professional I had to find ways of working around my stutter. I tried to conduct business without using the telephone. I could do this with the small town setup. I met people personally or used the services of the deliveryman. I had a younger boss, younger than most bosses. He was a nice guy and that eased the situation. We worked together in the design studio away from the others who worked in the main studio. We settled in well and with this kind of set up things somehow got better. I don't know exactly why. Maybe it was that that we had a good, easy relationship, I enjoyed working with design, the more creative side, and I always had a load of pretty drawings.

There was this one time I went to a presentation with my boss. I had done the work on the design. We are at the presentation and he fires all the shots. He starts getting tangled up and does not know what to say. I know the ins and outs of the design. I take over, albeit intermittently, and with the stutter, and save the day. I have the knowledge and they wanted to know. When you know your subject well and other people are desperately interested in the subject, they will put up with anything. The thing that really sticks in my mind is what he said when he got back to the office:

"Gareth worked well with clients. That young chap really knows his stuff." That made a huge difference because he saw past my stutter and recognised my talent. Through this time my speech got better and better but the stutter was by no means gone. If I got too excited and destabilised then I could blow-up pretty well.

I was more mature by this stage and now believed that girls were not so bad. My cousin and I decide to visit the chicks - the girls across the road. That's when Jenny, my wife and I met. Our first meeting went off well. Jenny was good for me. I don't even know if I stuttered or tried hard to hide it. It bothered me desperately but she knew nothing of it. I just remained "cool", as youngsters these days would say. The real problem was the follow-up and that was terrifying for me. The telephone was not an option because I would stutter far too much. I did not want to have big blocks and look like a stupid, like a real Charlie. I used the services of the deliveryman and so I survived that. The good thing was that I was able to speak to Jenny easily right from the very beginning. One day, I bravely decide to visit Jenny. I drive this old clapped car into the driveway and meet head-on with Father Bailey. Jenny isn't home, dissolve and I leave a stuttering message. Jenny returns and her father says "A

young man came to see you today. He stutters.” Jenny replies “ I don’t know anyone who stutters.” So I didn’t get away for too long with Jenny but fortunately my stutter has never been much of an issue with her. Maybe she will tell it differently. We were married soon after that. We were both young, I was 25 and she was 20. The wedding speech was a nightmare. This young buck just fell apart. I could have died a million deaths but I survived. We left Rhodesia soon after that and spent a honeymoon year in Swaziland. Footloose and Fancifree. I had no cares in the world and the stutter was less frequently on my mind.

Gradual decline...with upsets along the way

Not long after returning to South Africa around the 1960s we started an architectural practice in which I am still partly active to this day. My two partners and I had a long and fruitful business, which lasted for over thirty years. By this stage my stutter was still there but wasn’t of too much concern. Maybe it was because I was doing well and not stuttering too badly. I still had the big massive blocks and things. The process of getting through the pain has been gradual and it has stretched over a lifetime. I got by with the ums, ahs, and swallows... all those sorts of things. I went from one trick to the next assisting trick. Sometimes they would become millstones. I must have tried anything I thought that would help to get by but I don’t ever remember saying “Aha, that’s the solution!”

There are times during my work years when I would really crack up. Once we were preparing a sketch proposal for a big company. If they were happy and accepted then we would have a lucrative deal. A high-powered delegation assembles in our office, all smart-looking, mainly White gentlemen. We welcome them into the boardroom that seems bigger, colder and longer than ever before. We know we have to impress and convince them. There is a lot at stake. I worked for months on the project and it is time to deliver. The show gets on the road and my bit is at the end. I will answer questions about the design aspects. It is a long wait and not good for a stutterer. Painful. It is still really painful when they discover you stutter. You wonder whether they see you as a halfwit.

I hear my partner: “Gareth will now take your questions on design”. The designs are impressive and I let them look. I say “Hello, I am Gareth, a part of the trio”. I proceed to present the drawings. The drawings speak for themselves and they speak for me. It is important to be well-prepared. I know the answers and it goes well. I have the

odd block but get through them. On some odd occasions like these you get the smarty-pants character, a young know-it-all, who asks something technical questions, just to show off his new age computer skills. The question is not even relevant here. I get derailed... AND THERE IT IS I FALL OFF BLOCK BLOCK STUCK STUCK nothing comes out SPLUTTER SPLUTTER and I finally respond to his question and proceed to the next question. It really hurts. I don't feel good but I continue. I just have to. We do a good job. They are impressed, convinced and they accept the proposal. Nobody says anything about my speech. We talk about the drawings and future plans. I don't feel good but I get over it. I wonder whether it was that bad after all. We did get the job and they were impressed with my drawings. Maybe they didn't focus only on the stutter.

Social scenes are easier. I am at a party and I am quite okay here. I mix and mingle and really enjoy the company. There is not much of a stutter and I don't bother much about it, until I hear the voice: Smarty-pants, shooting his mouth off about the latest technology. He remembers me and we have a chat. He is the kind of character who may be well-qualified but really just a clever dick. I feel at a psychological and intellectual disadvantage and it could go either way with him. If I met him on another day in another place I would just say a little, not elaborate and walk away. Today is different because he makes me feel sufficiently niggly to come out with a fighting spirit. I assert myself by replying to his question about architectural form and aesthetics, using esoteric terms that floor him. It goes over his head. I know this stuff well. Suddenly I feel powerful, speak fluently and make my points. I will not let him get the better of me, and the words just flow. With people like Smarty pants it could go either way. I choose. There are not many people I find intimidating these days.

Learning to get on

As life gets on you also learn how to get on. Even when I did have my worst moments of stuttering in the practice people still came back. They didn't just turf me out after one bad stuttering affair. So obviously they recognised there was more to me than my stutter and I got used to that and then the stutter didn't matter that much. Of course I would have loved to be fluent. I have learnt skills to deal with difficult situations. I just figure them out as I go along. I always lighten the air by creating little side jokes especially if there is a degree of seriousness or pomposity about the whole thing. I break the formality by lightening the atmosphere. I establish relationships with people, get to know them better. It helps them to know me better too and get

beyond the stutter. I always do my homework very thoroughly. If I am running a meeting I will know all the items coming up. I would be sure of my ground and from then on it would be ad hoc.

PWS have communication as a big thing in their lives. In a strange way I have become more sensitive about communication. I can compare myself with Jenny who I know very well. I can pick up vibrations and things with people. I know what's inside people's heads better than she does. I think I can read atmospheres. It is like a sixth sense. I can sense when there is a degree of discomfort or if there is confrontation looming. Vibrations come from people not walls. When I know the situation like this then I can act on it. I diffuse the situation or soften the reaction. I am also good at listening and so this makes me a good communication partner.

On an even keel

The thirty years, between 1965 and 1995, was a time of stability and all that went on helped to make stuttering less of an issue. It was a lot less hectic and jangled than our young adult lives. You were not running around like a chicken with your head chopped off. The business and family were growing and I was on an even keel. I had the usual ups and downs, peaks and troughs but certainly more peaks than troughs. I was fortunate that I worked out of town. I went home for lunch every day and put my feet up and listened to music. Life was easy-going. The business situation wasn't as competitive as it is in these days. There wasn't so much of the sue-ings and doings. Our business was doing well and expanding. On the family side, my life was wonderful. We were blessed with three very beautiful children who were a joy. They did all the right things, went to university and all gained professional degrees. We had some upsets too like my daughter's divorce but we lived through those.

I never had any problems speaking to my children. I never stuttered with them when they were just waist high. I didn't have a hang up with them. There was this "me and them attitude" and that tends to knock out that fear. I am more powerful than them. I never felt that there was a problem on my back at all with them. I never used a single trick, not even the sly trick to hide the stutter. Perhaps it is because I talk to them in a different tone of voice. Everything changes when you deal with children. I don't think they were ever aware of their father stuttering except when I spoke in public. We never talked about it. The same happens with my grandchildren now. It is a great joy in being a father. Tenting was one of the best times to develop real bonds and we did

that often. Under that little tent with the rain beating down on the roof: you, your wife and three children huddled together ...the rest of the world didn't matter. In that kind of relationship and situation you feel good and stuttering was furthest from my mind.

In later years, the stutter was still there but a lot less frequent and I had my ways of dealing with it. The forces that held it together were no longer there. Even later on in my practice there would be the odd occasion when I would have a bad struggle and stutter. I would always have a side-kick, just in case. There would still be that block and free bit and people would look up at the ceiling. They would wonder and wait. I would have liked to be more sophisticated and slick but I just got on knowing that the work I produced was of good quality. I didn't care too much about what people thought anymore. We were also a good team and we complemented each other. It didn't seem to matter so much that I stuttered.

Supporting PWS

Some years before I began semi-retirement, I read of the launch of Speakasy around 1994, a support group for People Who Stutter. I joined with the intention of assisting those who did stutter. It sounds a bit arrogant but I thought that having lived with this problem for so long I might have something to share. I attended regularly and we have some interesting conversations. I always ask the chaps: Do you play sport? Do you have friends? How are you doing at school? Do you play music? Look at the other things. Don't dwell only on the stuttering. Think of yourself and all the good parts. Your speech may be your worst attribute but there is a whole lot more to you. Who knows one day, like me, it may very well be converted. I was a little fellow who couldn't say two words sometimes and now 65 years later I am at the other end and it is a fantastic pleasure. You have the choice and you can Become Someone. You can be burdened by your speech problem or you can have huge accomplishments. The longer you have fluency between blocks the better. But to get there you need to have the right frame of mind and feed on the good moments. The point is that it does not come from your speech alone... in fact things on the outside may have a positive effect on your speech. Confidence can come through many things. It is equally important not to see yourself as a stumblebum, and maybe then you won't be one. There is a lot more to life than stuttering. You must remember that amidst all the pain and suffering.

At one point at Speakeasy we did a media campaign to educate the public about stuttering. We wanted to convey the message that although PWS have a problem that is not what we're all about. We arranged an interview and it was terrible. The lady asked stupid questions. She wasn't knowledgeable and she didn't listen. Sagren and I answered the questions. She interpreted the answers and produced a ghastly article. It conveyed the picture that we were sort of imbecilic and groped for words and had veins sticking out of our necks. Of course our veins stick up! But she just conveyed us as poor, poor people with a problem. I read it and didn't like it. Although it was redone it still conveyed us as a breed of poor fellows. It was her story and she heard very little of ours. Since then I decided I won't talk to the media.

I was asked to do a radio interview not so long ago but I didn't. I am still scared of situations where I think I might crack up. I still think it is important for the public to know about PWS, especially now. We have reached new, exciting and difficult times in South Africa. Transitions are never easy but we have a democracy and the best constitution in the world. Human rights are currently on the agenda all over the place. It is a time when we realise that we all have our problems and we can talk about them. You mustn't close up inside yourself, become self-centred and think you're finished. There is a whole world out there. Interact with it and you will learn. There is a world with many problems and it gives you perspective when you step out of your world.

To this day I would still always say I am a stutterer but I am a lot of other things too. If I were honest as a schoolboy it possibly would have been the number one issue. I would have just ignored it even if I didn't want to admit it. I would have said I was the boy who got all the prizes. Everyone else would have said that little boy stutters. Those who knew me might have said I was a stutterer but perhaps a bit more too. Through University I was a stutterer and having observed me in the studio presentations they would have said that's a stutterer. But down the line a different picture emerges. Gareth the architect, Gareth the father, Gareth, the grandfather. Gareth the stutterer is still there but somewhere in the background. These days I give little attention to my speech and I speak to everyone. I have even become somewhat of a community spokesperson on the forums I sit on. There are just so many other things that occupy my mind now. Money for retirement, my son-in-law's retrenchment, Jenny's illness, the plight of orphans. There are the joys of holidays, sport every day of the week, symphony concerts on Thursday evening. From where I am now, stuttering is a non-issue.

SAGREN'S STORY

Re-invent Yourself

Early memories

I started stuttering when I was very young, probably when I was around three or four years. I am not sure what my stuttering was like in primary school. In high school it got much worse. I struggled a lot. I had long blocks and I used to slap my thighs, my hands would fly all over the place as I tried to force the words out. I avoided speaking situations as much as I could, especially at school. I avoided the telephone a lot. When I began work it got a bit better. I still stuttered and had long blocks. I began to use the telephone more and the fluency was a bit better. I did struggle with company presentations. I have very severe blocks when speaking to groups of people. I attended speech therapy for almost a year. I learnt skills to make my speech more fluent. Fluency skills were difficult to practise. It was difficult to use the skills outside of therapy. Over time I have been feeling better. I am more confident now. I still have blocks but I am generally more fluent. Ya. I guess that's it. Yes. That's my story of stuttering. You want to know about stuttering and my life? That's a whole other story. Are you sure you have time to listen. Are you sure it is relevant? Okay. Here goes...

When I was about two and a half years old I was teased because I didn't speak. The children in the yard said "Bhada Bhada Bhada. Sagren is a Bhada"¹¹. My mother couldn't handle the teasing. She tried to stop them but no one would listen. At the time, around 1968, we lived as a big family in Verulam, a semi-rural Indian community. I don't remember too much but my late grandparents would talk of the good old days when there were no lights then and we used to sit around the fire and talk. There were about four communal households shared between my uncles, aunts and grandparents. I was the only grandchild, the youngest and always teased. Eventually my mother got really frustrated with the teasing and she took me away to my maternal grandmother. I don't remember much about that time but I have this memory. There is this big ground where they have the fair. There's no bridge, just the river. It is raining and my mum is pulling me by my hand and carrying my little brother. Up the steep hill to the Village to take a taxi. We go to Mayville. My mum knocks at the door and my granny opens. It is so clear. I can still picture it. I stayed

¹¹ Bhada: Hindi word meaning stupid

there for about six months and then my mother, father and brother also moved to Mayville. But there was a lot more going on than my speech. My parents had a very bad relationship. My father always gave my mother a hard time.

In Mayville, life was better. I spent a lot of time with my uncle, my mother's brother. I have a very close bond with him up to this day. He walked with me every day around the neighbourhood, took me past the old bioscope to Bhanabhai's shop and bought me a quart of milk. I would have it while he sat around talking to his friends. I felt special in a good way. By this time I was about five, I started talking and stuttering but I don't have any early memories of stuttering. My first memory of stuttering is in primary school. Most of my primary school years seem to be blurred, with some flashes of vivid memories. I wonder if these memories are blur because I have blocked them out or because nothing significant happening then. I knew I was stuttering for sure by the time I settled into primary school in Chatsworth. With the Group Areas Act¹² we were moved to Chatsworth where only Indians lived. I was very lonely and isolated mainly because I stuttered so I began stealing my father's money to buy sweets to get friends. I knew very early on that if you had money, you had power and you had friends. That strategy didn't last for too long because I was caught. It was only later in high school that I had a close friend, which helped me a lot.

There are only two things that stand out about primary school. Firstly, the big size Afrikaans teacher who used to terrorise everyone. ShhShe what you all...(that's me trying to get the word out). She had an □□□□¹³ assistant named Convict who used to carry the cane around for her and she would hit on our legs. □□□□One day (I get through the stutter faster these days) we, the children, marched to the principal's office, stood on his desk and protested. She was removed and I learned that you can be powerful even if you think you are powerless. On my own, however, I was still powerless. Secondly, the children teased me. I didn't want anyone to know I stuttered and so I went through primary school like one of those children who sit silently in the

¹² Group Areas Act: Law formalising separate living areas for different races in SA.

¹³ □: Symbol representing a stutter

corner year after year. The teacher just left me alone. I don't think that everything was bad but I don't recall much more about school.

Home life was complicated

Home was a different story. I was very withdrawn because of my stutter but also because of very difficult home circumstances. My father comes in and everyone is silent. No one talks. There was no TV then so we have the radio on. We move away to the kitchen. We are very frightened of him. He is drunk and can be abusive. There is always some commotion going on. On occasion he would beat my mother and me. One time it got so bad that we called in the police. Things were chaotic then and they were divorced when I was twelve years old. It was sad because we lost out on a quality relationship with him. I remained withdrawn and my younger brother got rebellious. As soon as I came back home from school everyday I did my schoolwork while the other children played on the ground. I didn't want to join them. Fortunately, my uncle rescued me on a Friday afternoon. He took me away on weekends. There I played with children of my own age and helped him to build. I got back home on Sunday and by Monday I was back to being withdrawn. Life was difficult at home even after my father left because my mother had to work very long hours and we lost contact with her. I felt very much alone.

Small hopes and changes

My parents knew I stuttered but they would avoid talking about such a sticky subject. I wonder if it is an Indian thing. Up to this day we don't talk openly about such matters. I still feel embarrassed. It was a real pity because I felt very lonely and unsupported. It would have been great if they did something. I don't think they knew what to do about stuttering. They never heard of a speech therapist at the time. I am sure that if my mother knew of some place that could help she would have sent me because she knew how I struggled with speaking. But there was something my mother did which helped me a great deal. I was a boy scout and we had a parents day. We had to speak on Compasses. Compasses and directions. I am very good at this and did very well even with stuttering. My mum said to me "Why don't you become a teacher? I think you will do very well". Those words stick. I could Become Someone important. Teachers were held in high esteem then in the Indian community.

At high school I was still being teased. I could never say my name or answer a question without being stuck. There was the one time when we were all assembled at the beginning of the year so they could place us in new classes. The teacher calls the names of each child. She calls my name. Silence. I have a block. At the end the numbers don't tally and the principal wants to know where the problem is. The teacher whispers to him that I stutter. He announces loudly that she must ask me questions everyday so I get used to speaking. I am sure he was trying to help but I felt really embarrassed and made the situation worse for me. Similar things happened in class when they called the register. I respond with silence and the teacher would continue. But Lorraine would always say, "You missed Sagren!" She never got it! The teachers got used to leaving me out. I wonder sometimes if I was just a bother because I took so long to speak.

I was in standard seven, about fourteen years old when I formed a close friendship with my best friend, Dayalan. We were in different classes but played together in breaks. I was only comfortable with a small group. In a large group I always felt left out. We played cricket, had parties and I spent time with his family. I felt good being with him and he never bothered with my stutter. I can honestly say he is the best friend I ever had and we remained friends even as adults. In the class I did very well at Maths and Accountancy and felt that it was easier to answer questions in these subjects. Everyone soon knew that I was good at these subjects and I allowed them to copy my work and I got friends in this way. I even had the girls asking me to tutor them after school! Oral work in class was a nightmare and I hated English and Afrikaans. Most times teachers bypassed me when it was speech time and that was great. On the few occasions when I got called I was very tense. I couldn't say very much and they would let me sit down and give me an average mark. The teachers didn't talk to me about stuttering. The only time they were really concerned was during my matric year, my final year at school... I did well academically and they were worried that the external examiner would call on me during the moderation process. So I did an oral - which I wrote. The teacher asked the questions and I wrote the answers.

Getting on

I did well in Matric and I was proud of what I had achieved. I went to university for the first year but I had to leave to find a job in 1987. My mother lost her job and she was really battling financially. I applied for a job at the packaging company I am still with

now. I think God was on my side the day I went to the interview. The guy who interviewed me, Peter Smith, felt sorry for me after he heard about my family circumstances. I settled as a junior clerk and handed over my entire paycheck to my mother at the end of the month. I was the breadwinner and responsible for the family. I was on probation and proved that I could do the job. No one seemed too concerned with my stutter but I had to deal with my fear of telephones. For many years I let the telephone at home ring. A complete avoidance. When it rang in the open-plan office I couldn't ignore it because people would wonder what was wrong with me. So I answered, got stuck but persisted and slowly got used to speaking on the phone. I learned some of these skills from my father who also stuttered. When I began working I felt it was important to get in touch with my father again. He used to write letters to us and we visited him occasionally. I watched him at work. Although he stuttered, he spoke to his clients and processed all the orders over the telephone. I always thought, if he can do it so can I. He was a source of inspiration. I slowly conquered my fear of the phone.

On the personal side there was another happening which was beyond my expectation. I met a girl on the bus while travelling to work. We got to know each other and she didn't appear to mind my stutter although I worried a lot about the impression I was making. She liked me because I was an office worker, different to the other factory workers on the bus. I was young, handsome and well-dressed. Stuttering never came into the conversation and we were soon married. As a young boy in school I never thought I would ever ask a girl out on a date let alone marry because of my stutter. The marriage didn't last long but it had nothing to do with stuttering. At work I was getting on very well. I was promoted many times as I slowly climbed my way up the ladder because my managers recognised I could do the job well. I stuttered quite badly and this bothered me. Most times I remained silent at meetings unless I had anything important to say. I was embarrassed when I stuttered. They might think that I didn't know what I wanted to say or that I was stupid. Fortunately, I didn't have to deal with the managers on a regular basis. On the factory floor I got to know the workers and enjoyed talking with them. I soon got to know people well and felt less threatened.

My stutter was still bad and I felt I should do something about it. I tried speech therapy which I only got to know about for the first time when I was 22 years old. Before then there were no speech therapists around. I learned fluency skills, the soft contacts, easy onsets, mirror work which helped me for a short while. Although I tried

to practice these skills, I couldn't apply them skills in every day speaking. I continued stuttering and all the bad habits I learned like avoiding and changing words just so I could get by.

A terrible event

The real trouble happened when I had to do presentations on financial issues at meetings. There was one conference in Drakensberg which I remember like it happened yesterday. I had three pages of a financial report to present. Those were the longest minutes in my life. I stood at the front, nervous and tense, panicked and blocked. It took five minutes of struggle, struggle struggle, block, block block, to get through the first line.

I gave up and told my teacher - no my manager, that I couldn't go on. I was so humiliated that we left there. On the way back he said "Why don't you try this Dale Carnegie course?" It will help you. I knew about it but it was far too expensive for me. He insisted and even offered to sponsor me. I joined and that was a turning point in my life.

Trying my best

At the first session, we had to introduce ourselves and you know how people who stammer get stuck. The leader said "Don't worry by Session Five you will improve". His words stuck. It helps to develop your confidence. I didn't have a car but I attended every evening getting home sometimes at one in the morning. You have to be willing to try. Some people drop out. I wasn't willing to give up and I learned so much in each session. How to win friends, how to stop worrying and start living. I made a speech at every session and received awards for contributing the most. I thought that only I had a problem with speaking. Normal people – NO - fluent people have problems too. I thought people like doctors and lawyers were successful people with no problems. They all had their own issues. Life's not perfect for anyone and no one is perfect for life. Communication is a lot more than good fluency. It is about meaning and relationships. I learned strategies to deal with life. There was no focus on my stuttering. We did exercises like how to confront a difficult person or convince someone. You learned not to worry so much even when things are bad. You learned that things are always fluid, in motion, and you can't control it all. Enjoy life. Stop worrying and start living. Focus on NOW. Not yesterday. I am really convinced that if

you destroy my memory, every trace of it, then I will not stutter. My stuttering and who I am is built on all those memories. Even if something small or insignificant happened early on. It becomes a bigger problem over time.

Session Five is the Open Up session. I am easily able to present a poem about myself. In this session there is screaming, talking. Letting it out! I reinvent myself. My fluency improves because my confidence does. I still stutter but that does not bother me as much. I was awarded the prize for best student and appointed as graduate assistant. The programme works wonders. I know I will have to continuously re-invent myself. I must see things through new eyes. I realise the way I saw stuttering was the problem itself. I always had this idea that speaking was difficult, listeners were critical, and I was powerless. There is that famous quote that people only have power over with you with your permission. I find new ways of thinking about myself, my life and my stuttering. I learn new habits, habits that help me to be successful and happy. It's not as simple as it sounds. You must know what to do differently, how to do it and most important you must want to do it. I exited the programme positively charged.

As the saying goes when you are positive you attract positives. I think that is what happened. Things in my life started to change. As I climbed up the corporate ladder, I began to travel to many places in the world. In a short space of time I visited Zimbabwe, Kenya, London, Sweden and Switzerland. I had to interact with many people of all cultural backgrounds and I was finding that easier to do. I still stuttered but not so badly but I just got on with the conversations. I had to present at meetings and talk to many people. The funny thing is that I actually enjoy socialising, being with people. I learned how to build relationships with people. I join conversations, break the ice by telling jokes and do anything I have to keep the conversation going. When I stutter, or feel like I am going to stutter I just change words, avoid words, put in the runners and fillers to get by. Now it seems to come naturally even though I know it is a bad habit.

At the end of the day I don't want to show people I stutter, but if I, do I just continue so that the message gets across. People at work are used to the way I speak after being around for thirteen years. I honestly think that I make a bigger deal of it than they do. There is one lady at work who I speak to regularly and she even comments on how I am doing. Not long ago she said "You are speaking well". Sometimes I need a few nice words to keep me going in a positive direction. I am fortunate that at work there is no grand hierarchy and we don't call each other Sir or Mr. This has

helped because I feel at ease even with my managers and talk to them without feeling under threat.

I still prefer face-to-face contact to the telephone because sometimes I get stuck. I have worked out some ways of how to manage telephone conversations. I will call people rather than have them call me so I am prepared and know what I have to say. I generally make a point of meeting the people I talk to over the phone so that I feel that they are familiar. I often speak to the people at the Johannesburg office and when I go there, I visit them and then the conversations are easier. E-mail is also useful but I don't like writing long letters and my English isn't very good. I prefer to speak to people than write to them. I use the e-mail if I don't know someone or don't feel comfortable speaking to them but at some point I will attempt a conversation. I don't have any one way of handling a situation. I just do what I think is best. I even keep quiet if I have to.

Good things happen

Another positive thing that happened to me was my second wife. In our custom they say that a wife is Luxmi¹⁴. She brought good luck and joy into my life. Before I met her I had a few relationships that didn't work. I always wonder whether all this was connected to stuttering. In some ways I think it has to do with that. I was looking for someone who was mature, who could look beyond the surface things like stuttering and really know who you are. I was looking for stability and acceptance - maybe because of how insecure I felt as someone with a history of stuttering and other problems. Kasturi and I connected immediately at a blind date. Can you believe that? We just got on talking and she never even knew I stuttered on our first date. The next day I desperately tried to contact her, by telephone. It was late at night and each time I called I had a block. She hung up thinking it was a crank caller. I persisted and got a few words out. I stutteringly asked her out on another date. She didn't seem to focus on my speech. There was something else she found far more important. I asked her to bring her daughter along too and she fell in love with me for accepting her for who she was, a divorced single parent. Stuttering has never been an issue between us and I hardly stutter much with her. We now have three children, two girls and a little boy. I love being a father. I worry that my son will stutter but I think that I will be able to support him. I love reading to my daughters and spending quality time

¹⁴ Luxmi: Divine mother, goddess, and a symbol of prosperity in the Hindu religion

with them. I feel I have the things in life which are most important. At home my speech is not an issue. I don't stutter much.

At work I have continued to receive promotions. I sometimes have to pinch myself and ask if this is really happening. Within a year my salary has trebled, I have a fancy car allowance and an excellent job. Of course with the job comes all the frustrations and workload which can disrupt me sometimes. There are always the ups and downs, the presentations, demands and problems. I just deal with them the best way I can. I learned one very very important thing that helps me with my speech. Knowledge is power. When you are the master of what you are talking about, the person you are talking to will sit and listen because he wants to know what you have to say. I always make a point of being very well prepared for all meetings and presentations so that I know my facts and figures well. When I stutter no one seems to care too much. There are those who will say something but that is rare. Recently, we were at a year-end party where the Indians are famous for causing trouble. This time it was me. I was explaining something to the group of guys from the factory floor. I am good friends with them. I stuttered and this idiot began to imitate me. I saw red and kicked him hard while the others tried to separate us. I don't lose my cool often but there are some things that really get to me. All the other guys were also angry with the idiot. That was an isolated incident, but it still happens.

These days I am not ashamed to say I stutter although I don't go around advertising it. I joined Speakeasy, the support group for people who stutter in about 1996. I tell people about the group because it provides good support for PWS and I have benefited by attending. As part of the group effort I participated in a newspaper campaign, the famous Ebony and Ivory, campaign with Gareth in the group. The article was not a good one because the reporter only gave the bad side of our story and wanted people to feel sorry for us. I also took part in a radio interview that went better because I was able to share my experience in an honest way. Recently, I also phoned in to a radio show and gave my point of view. I think it is important for the public to understand who we really are. Although we know about prejudice and discrimination, I feel that PWS may be discriminated against especially when it comes to job applications. I often wonder if I should say that I stutter on the application form. I don't include it because I think that I may be eliminated unfairly because they wouldn't consider the other important things on my CV. When I get to the interview I will tell them I stutter because I feel it should not be kept a secret.

Living challenges

Life will always have challenges. Things at work have changed recently because the company made some major changes and people have been moved around. There are new people all over the place and now I have a new position as well. It is not going to be easy. Just the other day I was called to a trade union meeting where I had to address the guys. I wasn't prepared for it because I was having a busy day at the office. I went ahead and explained all the issues and I came out okay. In a situation like that there are two things that can complicate how I speak. The first is that my accent is often different to the Black and Swedish people I have to talk to, and the second is my stutter. I try to keep the communication going by presenting my side of the story in a simple, uncomplicated way. Race is not really a barrier because I have learned how to communicate with people of different backgrounds even across language backgrounds. My strength is that I have learned over time to remove the obstacles of race, age and language in order to get on with people. I started at a junior position so I have had the opportunity to interact with all people at all levels. I can get thrown if a group begins to tackle me like at the trade union meeting I try to remain friendly, in control and sort out the problem.

I have reached a point where I socialise easily and enjoy being with people. I speak when I have to. I accept stuttering as part of who I am, like my limbs. It is part of me. I will even tell people I stutter if I think it is necessary. I carry on with everything I have to do, with my stutter, I recently put myself to the ultimate test. I gave a speech at a family birthday party. Of all people they choose me to speak. Maybe because I talk so much these days. I prepare. This is a real test for anyone. I was nervous but I took a chance. I prepared well but there was no guarantee how it would go. Stuttering can come up at anytime especially when I am under pressure. I take the microphone and start with my usual style, joking. "They asked me to speak today because I am the youngest son-in-law in the family, best-looking and most intelligent..." The rest just flowed with a few blocks along the way. I said I stutter, and moved on.

When I look back on my life I wonder if all this is real. I am content with who I have become. Stuttering will always be there but it is not a major issue. I hardly bother with it these days. You have to keep moving, reinventing yourself.

THABO'S STORY

A Terrible Struggle

I wouldst though couldst stammer, that thou mightst pour this concealed man out of thy mouth, as wine comes out of a narrow-mouthed bottle; either too much at once, or none at all.

William Shakespeare

Takes so long...

ooooooooooooooooooooo1 llllll llllllllllll erer kn...knerer ererererererer erer that I ... since ...ooooooooooooooooooooo...

You don't understand what I said. I can see by the questioning confused look on your face that you don't understand. Here I go again. Read every sound.lllllllllll llllerererllllllllllllliili whwh DON'T GUESS PLEASE DON'T YOU WILL GET IT WRONG. Whwhwhlllllllllii

I look down. I can't look at your face. It is so embarrassing. Yes. I know what I want to say. I break the contact. You wait. Try to guess in your mind. You don't know what I want to say. I continue the struggle since I started it. More than a minute has passed. I stop. Try again. Finally, it's out.

I started st st st st st st ruggling ya st stutterting when I was in GGGGGGgggggggggggggggggggggrade one.

This is only part of what happens. The outside. Nothing comes out or too much all at once but you still don't know what I am saying. What goes on inside me is worse. Very very bad. I can see you are embarrassed too.

It is different each time. The block is a disability because it takes so long for a word to come out. When I talk people don't seem to understand what I am saying. They want to complete the words for me and that is the most irritating thing in my life. They often say the wrong words too. People will ask me to repeat or sometimes stop the conversation. With friends I don't feel so embarrassed and then I stutter less. They

understand me. When I meet someone for the first time they have no idea that I stutter. I try to maintain that status but when I get stuck then it won't be the same. Then I am trying to stutter less and hide it. I try very hard to hide it because I just can't handle that embarrassment. Sometimes people feel sorry for me and I hate it. I never say anything about stuttering. Every day conversations at the shop, buying a movie ticket are very difficult. I try to speak slowly, use my hands to speak or ignore the conversation by leaving. If I am with someone, I let him do the talking for me and sometimes I may just write it down on a piece of paper and read it out. Reading is easier for me. The bad days are those when I notice that someone has laughed at me. When I am alone I would think of the incident and feel like crying. The whole day would be ruined. The experiences just carry through the day. It will stay in my mind. Right now it is the biggest thing in my life and I will do whatever I can to make it go away. I try to hide it and get away with it. I hate making phone calls, going to the shops and asking for information. Most of all I hate people completing the sentences for me.

Tease Tease

I remember the first day I discovered the stutter. This happened when I was in Grade Two, about seven years old.. I was reading a book in front of the children in class. I was very shy and nervous and as a result I started stuttering suddenly. The children started to laugh. At that moment I wished the ground would just open so I could get under it and die. I was so very hurt that I nearly cried too. At first I didn't even know what the stutter was. I didn't even know why they were laughing. That was the beginning of my nightmare. Before that day I knew nothing of the stutter. No one at home said anything about it. From that moment I decided since everyone in the class was laughing I will just sit down, quietly, and say nothing. I did this for two whole years. Yes. Two whole years. That was very hard. I wanted to be with other children but didn't join them a lot because I would have to speak and show the stutter. I had two friends, Bongani and Nathi. They understood me very well and they never teased me. When I speak I get stuck and repeat words and struggle. The children laugh because I speak differently to them. Most of them laugh and some imitate me. In Zulu, which is my first language, we call stuttering Amalimi. There was this one man on TV who used to stutter. His name was Ndaba Mhlongo. They would call me Ndaba and everyone would laugh when he came on TV because he stuttered. I felt sad and embarrassed. They also teased other children who had physical deformities. I never teased anyone.

On the playground I was shy and reserved because of the stutter so I didn't take part in many activities. The children would tease me whenever I spoke especially on the playground when there were no teachers around. I always felt so ashamed and most of all embarrassed that I could not respond to those who were teasing. I really liked to play soccer but the stutter spoiled that too. One day, in primary school, after a training session the coach asks everyone. "What did you learn at training today?" It is my turn I try to say something but nothing comes out. Everyone just laughs at me. I am so embarrassed. The coach moved on to the next person and he asks the same question.

Staying in the background

In school at Sanzwili Lower Primary, I would find ways of being quiet and staying in the background. I didn't know anyone else who has this problem. I am the only one at school. I don't want to talk and be noticed. The teacher points only to the ones who make a noise in the class. So I will sit and not make a noise. I talk very little to the other forty children in the class. If you were well-behaved then the teacher just leaves you alone. If I talk and say the answers then the teacher would expect me to explain or discuss something, and that would show my weakness. I was silent during Grade Two and Grade Three. It was so hard. One day, a teacher, Mrs. Mashaba found out about the problem in Grade Four. She told me to bring my parents to school. I don't know what they talked about but she stopped me from reading books in front of the class. I don't think that helped me because I felt very isolated. I only spoke if I had to answer a question. But there was some oral work I had to do. It was the worst thing, the thing I hated about lower primary school was standing in front of the class and telling a story about myself or my family. I used to say to myself "Calm down! Relax. Go slowly". These things helped a bit. I got through the oral but not without stuttering. Speaking is such a struggle. It was a battle to get out every idea. Mrs. Mashaba would tell them to stop laughing but they still did.

At home it's different

Home was different from school. I stuttered more at home because I talked more. My relationship with both my parents was very solid. They are loving and understanding, especially my mother. My father was away working for most times. My mother is down to earth and very sensitive, like me. She also had a stutter when she was young but that went away. I never heard her stutter. She was always a very

good listener, especially to me. My mother was always there for me even though she was busy as a nurse at the hospital for mentally-sick people. She always comforts me and tells me it will go away in time. She told me that children used to also laugh at her. She says she was just as bad as me. I think the only reason I stutter is because I inherited it from her. She understands this problem and sometimes she tries to help and says "Don't rush and start again". None of this helped with my stutter. I used to get stuck but they made it easier for me to speak at home. I knew that she loved me and did things to make me feel special. I was more than just a stuttering child to her. I remember that on my 11th birthday she bought me a bicycle. These things made me feel good. I was generally a happy boy but I seem to remember the bad times better. There were also other people who helped me. My aunt also lived with us then. I talked a lot with my Aunt about the things we did at school and about stuttering. She tells me it would go away. My mother's brother is a lawyer. We are very close, still. I didn't spend a lot of time with him but I met him at least once a year at his traditional thanksgiving ceremony for the ancestors. He spends time with me and comforts me because of my problem.

Big Changes, New place

I passed every class in lower primary school. The report never said anything about my stuttering. It would say, "Well done, Thabo. You can do better. Satisfactory." I think because I was so quiet they thought I didn't know. While I was in lower Primary School, we lived in Edendale, which was known as Moscow. It was called Moscow because of the violence in the area. There was political violence there in the 1990s. I was young and understood very little about what was going on politically then. My older cousin, Sifiso, who was involved politically, would come home and tell me about what was happening... There was a struggle for freedom and leadership in South Africa. Moscow was a battleground for the fight between the political parties - the African National Congress and Inkatha Freedom Party. There would be strikes in the area, the roads would be blocked with huge rocks, and the schools would be closed because of the violence. I saw the killings and houses being burned and heard the gunfire. When all this happened we would hide or go away to my grandparent's house. I was always protected by my family but it was scary. When I finished lower primary school my parents decided that I should live with my Aunt who had moved to Ashdown because it was safer there. I moved to a higher primary school, Ashdown Primary. They also wanted me to do have a good education so I could one day live better than the millions of Black uneducated and unemployed people in the country.

Life changed a lot in Ashdown. Everything was new. At first it was hard to adapt to a new school and new area. My aunt worked till late at the local store and I had new responsibilities. I was just about ten years old then. I had to clean up the house and cook and do things I had never done before. I didn't mind because my Aunt believes in me and is always there for me. I get my confidence through her. My aunt and I are very close. Even when she is not around I feel like she is. She was never one to talk a lot. She will say something once but it was enough to teach me a lot. Besides the cooking and the cleaning she taught me discipline. She believed I could do well at school if I worked hard. I could become someone even with the stutter. She wanted me to have a good life and a good job. She kept me in line and encouraged me to be the best I could. If I even thought of doing something wrong, I would think of how she would react. So I took her advice and worked hard.

I can't handle the embarrassment

The transition to Siyahlomula High School was not so easy. The worst things about high school were oral work and making new friends. I would have been alone for a long time had it not been for my best friend Bongani who also moved to the same area. He introduced me to his friends and he told them that I stutter. It was through him that my friends started to understand this problem. I was very happy because I could interact with the others even when Bongani was not around. Then I wasn't so lonely. The problem was that I had difficulty starting a conversation. This doesn't help to make new friends. Even when I did speak I usually answer only what is required of me. Yes, No, and nod to keep in the conversation. I would really like to talk more but I stutter so much. I find it hard doing discussions and staying in conversations. I just give short answers and try to be pleasant. I never, never, never talk in a crowd or big group.

As I went on, even in high school, I try not to speak in class so that no one will know I stutter. The classes were big, about forty-five children, so all the children didn't know me. Sit down, listen to the teacher and say nothing. That was how I got by for most times in school. After a while I get good at Biology and Geography and everyone expects me to help them. It gives me a little confidence and I start engaging in school activities like oral work. I try to hide the stutter but it was very hard. I manage. I just tell myself "Calm down and Relax. Breathe. Just do it." But I never complete my oral work without stuttering. My speech did not change much and I was still struggling, but it was getting a bit easier, a little bit easier. I still never liked doing speeches. I had

this feeling that every time I make a speech people will laugh and I feel embarrassed. I was so scared. Besides being uncomfortable with my speech I just can't handle the embarrassment. I would absent or sick sometimes to avoid saying speeches. I make excuses and tell the teacher I didn't prepare the speech or pretend that I had no idea that it had to be done. I got away with it because they know the problem and they never said anything too. They played the game too. Sometimes the teachers didn't know that I stutter. When they, notice they just stare. They feel uncomfortable and say "Thank you. Sit down". It helped them and me but not completely. I had one very nice teacher, Mrs. Kraai, she helped me a lot academically but more than that she was very friendly. I didn't feel so bad when I was with her. I still tried as hard as I could to hide the problem in any situation. I try to talk very slowly. The problem was that no matter how hard I try to be fluent I still stutter. Then I get very low marks like 4/10 in the orals, but I get high marks when I write. That wasn't fair because I tried so hard, couldn't do it right and got low marks.

Back in the game and a bit easier

As I got to higher standards I worked very hard. I had good discipline, commitment and I used to study a lot. Because I knew my work well I used to teach the others. Then, I talked and speaking became easier. Those who did not know me well, got to know me and they also got to know I stutter. The more time I spent around people who knew I stutter, the better conversations became. As a result I was also popular with teachers. They got to know me and they would talk to me or ask me to send messages or bring back a response. I just hated that part because I would stutter. There were those who knew I was stuttering and never wanted to talk to me. Because I had other friends, I would just put that behind me. The frustrating thing was that the stutter did not change and I would keep telling myself that it would go away. I still avoided speaking whenever I could, especially the principal's office or with the teachers who were expecting too much from me. I felt better in high school because I was given a chance to prove that I was just like other children by being able to communicate with them. I was also better than them, academically.

I also got to play soccer again at school because I was feeling more confident. I like to stay and play with my friends and I was good at the game. Soccer is a big thing in the school and community. If you were in the soccer team in the townships, you were popular. That helped me to get more confident. I was also in the local community soccer team and I remember this one big Easter tournament. There are lots of

people. I am on the ground. I shout and call for the ball. There is no stutter. People notice me for my talent and I get along fine. They are shouting and supporting me. I gained popularity in my area and became really good. I really enjoyed myself.

All my friends in high school had girlfriends so I must also get one too. I had my first girlfriend in Standard Seven. I bravely went up to her and said "I love you". I was worried about the speech but I just did it anyway. Girls were easier to talk to because they were patient. She never showed she was troubled by my stuttering. It was nice to have someone to take me for who I was. I had a way with girls that was different from most boys. I think the girls liked me because of this. I treated girls with respect and understand their needs. I am a good listener and I listen to all their problems and I never lie to them. I never ignore or isolate them, like my other friends do. I talk to the boys but they always want everything fast and always disagree with what you were you were saying and you must explain further. But I also knew that not every girl in the school likes me. Sometimes they didn't like me because I was the competition, academically. I always come first in the class. Some stay away from me because it is difficult to speak to me because I get stuck. Some girls didn't like me because I was always with the group of bad guys at school and they thought I was a bad guy too. These bad guys steal lunches, isolate others and they would be violent. I was close to them. I could get protection through them but I didn't do what they did. These bad guys were my friends and they understood me. Stuttering was never a problem with them. In high school the students stopped teasing me because they knew me and saw that I was no different to them. They understood me better and I felt stronger even though the stutter was still bad.

The stutter is still there but I get on

Although things were better by the time I reached matric, my final year at school, stuttering still was troubling me a lot. Stuttering was always with me and people noticed how much I struggled. One day, a nurse in the neighbourhood told me that I could get help at the hospital in Durban which was very far away from where I lived. I didn't know too much more about the kind of help I would get so I just left it. I was getting worried because I knew that someday I would need to go out and find a job. Finding a job is not easy. I will be required to undergo an interview and maybe the job will need me to speak a lot. But first I had to focus, to pass matric. There were five of us in a study group in matric. We studied together everyday. I did very well and came first in March, June and September. That was a real achievement for me.

In the group we set out questions about the things we didn't understand and then anyone who knew the answer speaks. I used to speak a lot and try to keep the breath going and this helped a lot. I was good at Geography and Biology and I talked a lot because I was the one who seemed to understand better. When you are good they will listen because they are expecting so much from you. I still stuttered but it was much easier. When the teachers got to know I knew the answers they ask me to explain to the whole class, especially in matric. The start is always difficult but it felt better after I spoke. I tell myself "Don't be afraid. All these people are your classmates. Just relax and do it."

All my hard work paid off because I got a matriculation exemption. I passed. Only three of us of a group of 304 got an exemption. In our group only me and Nathi passed. Bongani failed because he didn't study enough because he had to look after his grandmother. He had no parents and no one else to help him. Nkululeko was very naughty and liked guns and violence. He got caught for stealing liquor and drinking. Stembiso studied hard but he and Nku would drink. I passed even with my stutter and that was my greatest achievement. My aunt was the one who kept the discipline and made me believe in myself. There was also one teacher in primary school who said that a person who stutters is very clever. I proved her right. I sometimes feel that my life is a disaster with this problem but luckily good things also happened.

Admired, but still struggling

The next step was university. It was a great achievement in my family. There was only one other cousin of mine who was at University. Black people were only starting to get into Universities in the 1990s. It is important to go there. If you have knowledge you have power. My aunt wanted me to go to University and make something of my life. I liked to be a male nurse. I really liked their uniforms but I didn't like blood and needles. I choose surveying because I didn't want a job where I have to speak too much. There was no place there so and I was advised that there was place in Tourism. I didn't know much about this but I did it to get into the University of Durban-Westville. After enrolling for a degree in tourism I realised that I had two career choices. Tourism Marketing or Management. I will have to speak for those jobs and I must do something about the stutter. My life is changed now also because people respect me now that I am at university. I am happy with what I am doing but the stutter is still a big problem.

I have been at University of Durban-Westville for nine months now. I have settled in but speaking was a big problem when I started. I was scared and lonely. I couldn't find my way around and I was too scared to ask. I don't speak in class unless I have to. I know I have to speak at university. I worry about that. It was very hard until I met my first friend in a tutorial after many weeks at University. We get on well. The thing that helped was that I told him I stutter and he understands. I had to tell him otherwise he will think that there is something wrong with me when I take so long to speak. Now that he knows, it is easier. The only other person that I am comfortable with at university is my female friend Wendy. The stutter is still bad. When I stutter now my muscles in my mouth and throat becomes so tight and I can't breathe properly. You need to remember to say the words you want to say. Sometimes I get stuck for so long that I forget what I want to say. I panic. I feel that there is no air inside my lungs and my stomach cramps. I am very nervous. I try to control the stutter but I can't. I change words, change languages and do anything I can to get on. After a long conversation my muscles will be so tight and I become tired. Then I want to sleep. I feel embarrassed.

Help in sight

I was in a tutorial class when the mentor asked me if I want to have speech therapy for my stutter. I thought about it for a week. I was so afraid to go because I know that the first question they ask is "What is wrong with you?" Since I had never told anyone much about stuttering I would find it embarrassing. I went because I thought maybe they have a cure for my problem. I thought they were going to operate somewhere on my throat or give me some tablets or medicine, like going to a doctor. It wasn't so bad after I started talking to Selina but I was so disappointed when I found out that there was no cure. I thought the world was ending that day but I carried on because she promised to help me with my stuttering. I have been enjoying therapy. We have talked about things like voluntary stuttering and openly stuttering and some breathing tricks to calm down. I know it may never be cured but they will help me to control it. I hope the stutter will be less. I tried some techniques I learned at therapy with my Uncle. He always wants me to talk normal and fast. I told him to wait until I finish. He just looked at me because I never talk to him like that before. I hope that one day I will be confident and that my speaking problem will be solved because I will be able to control it.

HENNIE'S STORY

Packaging and Presentation

Struggles and battles

Right now everything about stuttering frustrates me. Stuttering is standing between me and my dream of becoming a top-class business consultant. I am at the stage where I am really, really FED UP. I am at a stage, where I say, if my speech doesn't improve dramatically, then my life is a misery. Stuttering is for me just my inability to convey messages in a verbal form. My mind will be occupied 99% with the word I am pronouncing and not thinking of what I am going to say next. I sound DOF¹⁵, Stupid, whenever I speak. Stupid because what I say wasn't placed correctly in the sentence because I didn't have enough time to think of them because I spent most of my time thinking how to pronounce these words. At the end I say so little. I just sketch the picture, no details, only the outline. I can't convey my emotions. Only lines, no details. Word economy. Emotionally empty. Never state the obvious. But that's not all.

Imagine this. I walk in the door. Tall, Blond Macho Strappy, Rugby-playing Hennie. Next to me is the guy on the wheelchair. His problem is obvious. I look normal. I open my mouth to speak and ... NO. The game is not over yet. Not over till I stutter. Then it happens. Out of the blue. It takes me by surprise because I don't know exactly when it will pop up and until it does I am normal. You're not in control of your mouth and that is it. That's what really is annoying me. It happens. It takes them by surprise. The stutter does not look nice. It looks odd. Your face pulls in a funny way and you have the neck jerks. The game is over? Not yet. The hardest part is to look as if it is not the end of the world. Put up a front. Yes. So now a new struggle starts. I have to struggle from being a stutterer to get back to a normal. The only way I can do that is by not stuttering. Then that tune plays in my head. Don't stutter. Don't stutter. You battle on. Lean over to the normals, from the dark side. Lean back from the dark side to the normals lean back again to the dark side. If you stop and choose silence you lose the race. So I persist. From dark to normal. Through all this you just hope that you can make them understand that there is more to this person than just the stutter. I am also another normal behind that abnormal stutter. There is still that normal man

¹⁵ Dof: Afrikaans word meaning stupid.

with the wit and knowledge to speak his mind. The worst is that sometimes I forget that normal man and then I am the abnormal. ABnormal.

When I start to speak I feel small. With all this finding, swopping, chopping and changing words you still stutter. It's your self-image, it just deflates when you start stuttering. I've never in my life seen a stutterer with a strong self-image, never happened, not while he's stuttering. Your image will never stay intact as long as you stutter. It all depends on my situation, where it is, with whom it is, how I am that day. If you had an excellent day and you stutter a bit your image just gets lower. It might not be completely slayed. It's terrible over the telephone because they are expecting you to say your name and HELL! I stutter on my name. Hennie. See, I just said it now but you won't believe how much I stutter on my name. There will be a l o n g silence. No word. Nothing. It just sounds so stupid. The other person is saying "Hello, Hello are you there?" Its like a broken telephone line only the line isn't broken, I am stuck. It is such a battle doing what is so easy for others and even for me at times. Everything about this damn stutter frustrates me! The words I can't say change all the time and over the years. The other day I can't say my name. Ferrari is off this list. You know these words well and they don't come out. There is no order or sense. Just unpredictable. If I remember the word I got stuck on, then it will also get stuck too. There are always new words I can and can't say. I can't wait for Hennie to be off the list. The pressure does not always come from the new situation or environment or person. It comes from the pressure I place on myself when I fail. I just think Gee! You sound dof. Really DOF. I don't even like the sound of my voice when I am fluent. It always happens when I am interacting with others. I know that because I don't feel the pressure when I talk to myself and I do a lot of that. You can't stutter then. Not a single word when you are on your own. I didn't stutter with my older son, Johan, when he was a baby, but as he gets older, I am afraid that he will recognise that I have the inability to speak like the rest of the nation. I am just intimidated by that. I have less blocks and less stress when I talk to my parents and brother. There are some people I just get on with like the boss I have now, and then it is no problem. There isn't too much struggling.

I have a perception of the reaction of others. It is my perception of what I would feel like if another stutterer walked in. Maybe it is also their reaction. Maybe just a mixture of the two. Sometimes when you walk into the room your image is already broken because they already know you stutter. I have observed how people react to others with speech problems with much less of an impediment. As soon as they recognise

the problem they focus on that and the person's image is lost. It happens over and over these days. Hundreds of times. I hate it and I can't get used to it.

Worst stop possible

As I said before. Stuttering is huge, especially when I am 30-something. it is hampering my life and standing between me and my dream. I want to be this top-class business consultant and that is going to take Everything. It's gonna be your knowledge of the subject, number one. Speaking, relating to people, making speeches before people, working with them and their businesses and their personnel. I know it will be really involved. It's not the man in the street I will be working with. They are hard-nosed business executives. They want it to HAPPEN. They want they want it NOW. It's a man that has already made something of his life. They work hard. They don't stop. They are economically-driven, powerful and rich men. I am going to help get them richer. To get into the game I will first have to convince that hard-core business-minded man why I am the specific person who will be able to deliver the goods. They have strong beliefs. They have their ways of thinking and they don't just take your word. High flyers, strong-willed and wise. They KNOW and you have to be able to convince them. If I had to put them on a continuum, they are at the right extreme end. The worst stop possible. The all-knowing, successful, rich, White, powerful, male executive.

But nowadays it's not what you say but how you say it. That's how you are judged as a human being. There's this saying. If you are a rep, people don't specifically buy your product but they buy you. It's all about the packaging and presentation. How do I then sell my product. My product is me. I have to sell Me in this business I want to own. I'm not really marketable because of the stutter and that's the problem. They will never take someone who stutters seriously. As soon as I stutter they will think I don't know my stuff. To make things harder I will be in strong competition with other people as well. Maybe it won't be such a problem if I didn't want to be a big shot, but I'm not happy with mediocre nine-to-five work. I want to have more and I'm expecting more out of life. If I was a normal man-in-the-street it would be a completely different scenario.

Never always like this

The stuttering was never always such a big problem as it is now. I don't believe the stuttering i.e. the speech and the blocks itself has evolved or changed that much. Standard One, in the classroom. That is the first moment in my life I realised it. Hey! What? I can't say Ferrari. Ferrari. I remember that well but it was no big deal. My family say they hardly recognised it. No one reacted to the stutter. My parents concentrated more on the things that make you an Afrikaner. Knowing where you arrived from, the history of your nation, the language and your religion. We had a strong Christian upbringing and our parents wanted to instil firm beliefs about how we should live, like tell the truth, and that sort of thing. My father never really punished us. They were easier-going than the rest, not the staunch Afrikaaner, not the extreme Verkramppte who are conservative, hard-line right-wingers. I really don't recall any talk or them being worried about my speech at that time. Life was very nice. Stuttering was there but I never let it rule my life. I was the youngest in the family so I would always hang out with my brother and sister and their friends. I learn lots of new things with them and then I am more up to date with newer stuff than my friends are. We had fun when we got into teams and play Glyblad. It was a mud-flinging game we played between the English children and Afrikaaner children. It was just friendly competition. I was always with my mates and don't recall any problems with them.

In primary school, I was rather naughty and popular even when we moved from East London to Durban. I went to an Afrikaans School in Pinetown and I could get on with everyone. I was an average sort of pupil and I would be in the B class. I was always involved with the A-class - the intellectuals and the headboy, the leaders, and with my own classmates. I was on a friendly basis with everyone. I knew everybody and everybody knew me. I think I was just this way. It's my personality. Maybe it is just how I had to make up for the stutter. There was some attention to my speech when I was in Standard Four. It was probably my mother and/or teacher who were worried. I went to stuttering classes but I think I went more because I also had a lisp. I couldn't say the S sound properly. I think that they believed that if they sorted out the lisp then the stuttering would go away. Therapy wasn't too bad. The lisp went away but the stuttering stayed. It should have been the other way about. Other than that there was nothing much that happened with my speech then. There were no rude or difficult memories then. It was a lot of marbles, bicycles, and skates.

The trouble starts

At Gelofte High School, which was also Afrikaans the trouble starts. The growing up stuff happens. The first thing is that you enter the school and you are a little boy. Like a baby again. No more big boy. They have a go at you from the time you enter. They do this initiation stuff. I got saved because my brother was the headboy. Then you start learning new things, actual facts and you realise, Hey! You are getting on with life. Now it wasn't a matter of just playing. You still have the friends and company but now they are becoming more evolved, more critical in their thinking and more sophisticated. Now it wasn't so much that they were listening to WHAT you said but also they also wonder HOW you say it. It is hard to be popular here because now only a few people know me. I was always in a bunch with my friends and with them speaking was a whole lot easier. They were never nasty but they pull my leg about my speech. They didn't really tease me. I suppose they were scared I would knock them over. Only joking! I would never do that. I am not that kind of guy. I think that because of the stutter I was always willing to do more work to make myself popular. I didn't mind helping the others out. I will stop what I am doing to help out and that made me a good, reliable friend. It made up for my lack of speech. The teachers knew I stuttered so they asked me to read aloud only now and then. It was a happy situation because I didn't want to read by then. I read a lot on my own, not to make my speech fluent or practice speech techniques - but to learn new vocabulary. I realised that my speech was more fluent, the communication was better, when I knew more words.

By the time I reached standard eight and I was sixteen years old, the stuttering was burning my butt. The speech hadn't changed much but now I was bothered by it. I remember this one afternoon when I walked home and kicked every stone on the road. I was so cross I even want to to to to ... hit the dog. Only the dog will bite me. Just so cross. I just went to sleep. I wonder how my best friends would have seen me. Let me phone a friend. He was with me from primary school to high school. Hoe gaan did Meneer?... (How are you? Sir). He said in primary school stuttering wasn't too much of a problem but it was more noticeable in high school. I was more outgoing then that I am now. I suppose I did still get around then. Talking about getting around, you also had to get around girls. The girl situation was dry until standard eight. I would walk over to the girls sometimes and speak to them because they are easier to speak to. They don't seem to take notice of me. That's not good so I had to work a plan. My best friend Steve is a ladies man so I attach myself to him

and then I get noticed. Steve was my spokesman. If I liked a lady I got him to do the talking. But girlfriends never lasted more than a week then. As we got older, we were in bigger groups. Girls and boys were together and then it was more fun. Easier access. The girls never said anything to my face about my speech. Girls can be bitchy so I don't know if they laughed behind my back but to my face they accepted me like I am. By this stage at school I knew everyone better and I could clown around. I got on well with everyone.

Because of my popularity I became a prefect and rugby captain. I was also the Sergeant Major in the Army. Maybe they did see other talents and not just the stutter. In the Afrikaans school in the 1980s we have a period every week where we do Army Stuff. We have speeches on the Army and shooting lessons. I was the leader when I was in matric. I shout

Links, Regs! Links, Regs! (Left, right)

Trek op die linker kant! (Turn around).

Voorwag.! (Halt)

Maar links, regs!. Links, regs!

I was rather assertive and when you are shouting then they must listen. When you are assertive then they listen. I never stuttered. The words were automatic and we march to a rhythm. Unfortunately, I left the assertiveness there. I believe I lack assertiveness and confidence now. Stuttering was a problem back then but not as bad as it is now.

Lost in the Masses

Next step. University. It was expected that we would all go to university. I stayed at Res (residence) at Rand Afrikaans University and studied accounting. I believe I chose I career where I wouldn't have to speak too much. We were a very close-knit bunch of guys, many of whom were also in school with me, all stacked in these little dormitories. The stuttering was there but never so much of a problem. It was all about sport, partying, drinking, girls and of course studying. Lots of fun. You would think that I would keep quiet because I was scared of what was coming out of my mouth and making a fool of myself or that I would be reserved. But hell, I made a racket whenever and wherever there was a need to. I am such a party animal. A bit of alcohol and I lose inhibition and the stutter.

There were the odd times when I would have liked to be a bit of a leader and stand up and speak my mind at Res meetings but I didn't because of the stutter. Sometimes it would bother me in the lecture room but luckily I would be generally lost in the masses. There would be between one hundred to one thousand students in a class. Now and again the lecturer would say "OK, What is the answer? You there in the blue sweater." Luckily they never ever picked me ever in those three years. The stress would be there and it runs bloody in and out of your body, like a freight train BBBBB. I was so scared that one day it will be my turn. That kind of situation can help or flatten you depending on how you will rise to the occasion. I was never put to that test. Other than that, the stutter wasn't much of an issue at University.

I left University with a degree and a girlfriend who is now my wife. She didn't seem to bother with the stutter but would threaten me if I got any more rowdy. During my last two months at University I had therapy with a lady in Alberton. I was worried about how I would manage with the stutter in the world of work. Ya. The Alberton lady, the therapist, was nice it really helped me but it only lasted for a short while. I'd leave there on Friday and then for one day my stutter would be there far less than normal and then the relapse would just occur. I don't remember that much of the specifics, just slowing down, exhaling before the word, changing speech patterns. The stutter just stubbornly stayed. Maybe I didn't put in enough effort into it.

World of Work...the pressure begins

Then, it was the world of work in the early 90s. Many of my university mates started out at the Receiver of Revenue, and I did too. I filled in the forms and got in. There were no interviews. The stutter was not so bad and not so good. I was part of the Special Investigations Team. We wrote our names in invisible ink. Nobody knew about us until suddenly the whole lot of us do a raid on those who have not paid their taxes. We are the hit squad and seize all his records and documents. Then you meet and tell them they owe you a million bucks. They scream and shout. I young and new and luckily I was always with someone. At work, they all knew I stuttered but no one ever said anything nasty to my face. I don't know if they did behind my back. There was one lady who gave me a hard time because she didn't like men and Afrikaaners. So I was her pet hate. She gave everyone a hard time. I wasn't scared of speaking at the meetings but I let the other guy take over because he has all the knowledge. I would add in stuff if he missed it. There was one time when something happened and

he just didn't speak. I did. I know when I have to speak and then I do. I stayed in that job only for nineteen months.

Then I started a money-lending business which I got into accidentally by helping a friend because he wasn't available during the day. I was involved with the business, full-time, making loans and dealing with staff. It didn't take me long to get involved with the staff and I believe that helped a lot. They all knew me by my name and it worked out well. I lent money to everyone from window washers to bank managers. My speech was not too bad. If I have bad days I try wash them away. I try not to remember them. The business was very stressful especially in the first few months. At the end of the month you worry so much that you almost get ulcers. There is so much money out there and you must have faith in other people you don't know. This kind of stress can make your stutter worse and kill you. I am too kind for this job. I am not the kind of person who would break someone's leg for R 500 like others do. It is a good business which I still have but I wanted to move on. I got my father to help me there.

Stresses get to me...

With all these stresses, the stutter was getting bad and so I tried therapy again and again. First at the local hospital and then at the lady attached to a school. It didn't work out. We did the speech techniques and stuff and I always hoped to stop stuttering. It never happened. None of this was helping me actually. I practise a little and try to use the techniques. It didn't work. Maybe I'm really stupid. I don't do a lot of the work and I should. The problem with the techniques is that when I am outside my mind would be elsewhere, on daily business and not as much on the speech. I believe that the techniques work but that you first must have self-confidence. Then once you do the stutter it won't completely deflate your image and you can follow on with what you're about to do. You can use your techniques when you have a good foundation. The thing with the stutter is that one day you are feeling good and next day you're feeling bad. Then you say "Hey! Listen, it isn't working". Your moods and well-being would be more of an influencing factor than the actual speech. If you have a strong self-image and you really believe in yourself, even if you have a bad day, it won't affect you that much. I don't really relax. I don't have any methods to make the stress less. When I feel stressed then I feel out of control and then I struggle.

There are all the daily stresses that can disrupt you. A good day or a bad day classified by how your speech is happening for most time. I suppose its not just that. A good day is also when you don't struggle around each corner with your daily work, when things run smoothly and even a bad day at the golf course. When you work hard and at the end of the day you can walk out feeling satisfied. A bad day is just a grind. Sometimes, the days just stay and drag on. Then I have good weeks and bad weeks. Just a rollercoaster. When I am down at the bottom, I just swear. I hang in there and it does change. You have to do things that make it lighter for you. You just switch to something nicer. I have to lay this strong foundation to become more confident to rides these waves. It is a part of me. I hope that is just a normal part of me. You couldn't exactly call me a quiet guy when I am with friends. With my friends I mostly speak Afrikaans but when I am with English I stay with English. Often I switch languages because I stutter. I use humour a lot. If I meet a stranger I try to establish a relationship by joking.

Between all of this work and stuff we were married and had our first son and recently, our second son. I am so relaxed with my wife and my family that I hardly ever stutter or bother with it. I have no problems with my little boys. Occasionally I have a big block but my wife and friends don't seem to react to it. What worries me is I don't speak as much as I would like to these days, even with friends. Now as a family man I must get going and make a future. The first step is that I must get my articles. I started serving my articles and I am on my way to becoming this successful businessman but the stutter is really getting in the way. For the last couple of months I have the fear of speaking and I dream of stuttering every night. Nightmares. I had enough. This is so far from the dream I really want to live. That's when I told my wife to phone the university. I need some help. Right now! I realised that for me to fully develop my skills and be the person I want to be I need to reduce my stuttering.

Getting help

I started therapy at the university hoping it would disappear quickly like a lightening bolt. But I know it will be a process. We got off to a good start because Thej really understood me. I believe they would have helped me most cause they don't only minimise the stutter. They deal with you, and your life and the stutter. The way you see yourself is very important. I believe the stutterer should be involved with about 75% of this whole situation and the speech therapists would do the rest. We started with the advertising but I found that very difficult. I am willing to try. All my life I have

tried so hard not to let anyone know I stutter. I just feel that if I say I stutter I will not even be starting the race. Then the riots started at the university in June 2000, the therapy stopped and I left my bloody hopes there. I couldn't go back there when they started again because I started my articles.

At the university they told me about the support group for PWS and I joined. I attended every session because it has really helped. The other people there remind you that there are the good sides. When I look at it there are. I have a beautiful family, wonderful friends, holidays. I have lived life and it is not all in vain. I still focus too much on the stuttering. I still have the problem with confidence. I must be lacking in my mind. A friend told me about the Dale Carnegie course which helped his father who is the head of the police force. That's what I need. I must build my self-confidence. I must have a strong foundation. When I am finished this course I will ask myself, "Are you afraid of speaking in public? Will you answer questions in a group. Can you think on your feet?" If my speech is not perfect, that's okay. But I want to be able to think on my feet and not just think about whether I will stutter. I have even put my articles on hold so I can concentrate on this course. Ya. That's the story for now.

NONTOKOZO'S STORY

Little Hiccup, BIG problem

Back then, it was okay

In the early years, everything was okay. Things were fine when I was a child. My first memory of stuttering was in standard three when I was about eight years old. I don't remember anything about it when I was a young child. We lived in an African area Mandeni, where I started school. Then we moved to Umlazi, an African location south of Durban. It was around the 1970s. Life was okay with my older sister, younger sister, brother, and my parents. We did the usual family things like go on holidays, have picnics, celebrate Christmas. I don't even know if I started to stutter before then. I haven't asked my mother so I don't know if she knows. It is not something we talk about at home. My mother's brother has amalimi, a Zulu word for stuttering. I have not had much contact with him. When the stutter started it was so small, just little hiccups. I wasn't so fluent but it was minor. It just happened. Most times only I noticed it. No one said anything at school too.

In primary school I was very talkative. I was also highly active, a tomboy. I was just a normal child. I liked to run and play like everyone. I was the most active of the lot at home. I had a few close friends but mainly at school. We were not allowed to talk to anyone on our way home from school. We had to get home and remain there. Umlazi was a dangerous place. There were taxi wars, rapes and muggings. We didn't play outside very much. Our parents were strict and they wanted us to study hard and be good children. My mother was a schoolteacher and my father worked for a petrol company. They had better jobs than most of the other parents in the area. The hiccups were there but I talked a lot in class. I answered the questions in class because I was good at school. I was always in the top five. Most times my speech was okay. I did the poems and plays in Zulu. I was fluent. We spoke mostly in Zulu at school and home.

From hiccups to blocks

The problem started in high school in 1982. My parents sent me to Sacred Heart, a Convent boarding school in Verulam, north of Durban. They sent all my brothers and

sisters to boarding school. They wanted us to have a good, disciplined Christian education. It wasn't safe at township schools. Unlike the school in Umlazi, the Convent school was confined. There was less influence from the outside. This was a very big change for me. I didn't want to go there. Everything was so strange. The school was run by white German nuns. The nuns were very strict.

We follow rules.

They spoke English. We spoke English. We were Black, Zulu speaking girls at schools but we were only allowed to speak English. We spoke Zulu only when we were together.

You couldn't go off the school premises.

Wake up early.

Walk in a straight line.

Behave like girls.

Sleep early.

I was sad and out-of place and the stutter became very severe. From a hiccup I went to having big, long blocks.

Tttttttttttttttttttttthe wwwwwwwwwwwwwords wouldn't come out.

I got stuck for a long time. One minute to say a word with great struggle.

I stopped speaking so much. I became reserved. I also couldn't cope academically. Everything was very new and strange in the first year. A safe environment? I went home only on long holidays. My parents wanted me to pass. My speech wasn't as bad at home. My parents never said much about it. I don't know how but I passed Standard Six, my first year at high school. My speech was still bad in Standard Seven at school. The teachers at school noticed my speech. Everyone knew the problem. They didn't say anything. They left me to finish what I was saying. It got bad so they arranged a speech therapist for me. I went to therapy at the Convent attached to the school. I was happy to go. She taught me to prolong the first word to make my speech fluent. The girls in class would laugh at me so I stopped doing it. They thought this new speech was funny. I stopped going to therapy after a few months. The children didn't tease me when I stuttered, but they did when I used the technique. Although the therapy didn't help, I started to feel a bit more settled in Standard Seven but I was still finding the academic work difficult.

A bit more confident

In Standard Eight I was feeling more confident but my speech didn't change. I was still bad. The schoolwork was still difficult but I was doing better. We choose the subjects we wanted to do. I choose subjects that were needed to study medicine. It has always been my childhood dream to become a doctor. I worked hard but hardly spoke in class. I had to do the orals. I got stuck when I spoke in front of the class. I had to complete what I was saying. I feel terrible. I just want to sit down. Some good things also happened in that year. The school children voted me as a prefect. I was a bit popular because I took part in school hockey, tennis, swimming, athletics. I swam in the school galas. I did well at many things. I also joined the choir because it was one way to get out of school. I never had to worry about the stutter. The words just flowed and I was the same as 60 others. We sang outside school every weekend. We even met President Mandela! I shook his hand! We also met Stevie Wonder at the airport and he sang for us. It was nice in the choir because I was with my best friends.

Once I joined the debating team. I took part but it was hard. I was stuck for long. I couldn't make my points because I couldn't make the time. I liked to debate so I stayed with the team. I helped them to prepare but I didn't speak. I still did oral work but I got low marks. There were school plays but I didn't take part. I was active outside class and quiet inside. The teachers never said anything much to me. We didn't interact with them very much. I only answered questions if I had to. When I got stuck it was really tough. I feel bad. It would have been better if the teacher allowed me not to speak especially when I got stuck for long. The marks were still bad so it didn't really help to speak. I was still a prefect. I used to supervise class. I didn't have too much of a problem when I was in charge. I could also be strict. My speech was better when I scolded the children. I had authority and privileges. I was okay with friends. The stutter didn't bother me all the time.

The stutter was still bad in Standard Nine. My results dropped again. I still wanted to be a doctor but now I wouldn't voice it. I knew becoming a doctor was only for people with straight A's and I wasn't doing well enough. My parents always said "Study, work hard". In my final year of school I started working very hard, especially on Maths and Physics. My results were getting better. I applied for medicine but also for Speech therapy and Optometry. I wanted to do speech therapy because I wanted to understand myself better. I had to wait and see if they would accept me.

Accepting me?

When I got my matric results I was so happy. I did much better than I expected. I got an A in Maths, a subject I had been failing. My results were good and my family had a braai to celebrate. I was accepted for Optometry and Speech therapy but I was wanting to do medicine. I was called to an interview for medicine. The stutter was bad but I tried. They accepted me because I had good results and also because I stutter. Yes. I got into medical school because I stutter. Let me explain. I applied for medical school in 1999. This was after apartheid and the access policy at tertiary institutions was changing. They wanted to admit Black people (Me), female (Me) people with disability (me with a stutter) and good academic results (Me). How did I know that I was accepted because of my disability? They told me. I also had a friend who had better results than me but they accepted me. I was happy but I don't see myself as disabled. I can speak but the stutter is an obstacle. They also took in one person who was had a gait problem. It made the institution look good. That's how I got in. At another time in history I may have been excluded because I stutter. I don't think unfair discrimination is a good thing. I was happy that the policy was changing. My dream was coming true. I could be a doctor. It was great

Medical school was tough in the first year. Everything was so new. The place, students, lecturers, the subjects. I only knew one other girl who was from my school. It was a big gap, a jump from school to university. The hardest part was interacting with people. I remained quiet. My speech was bad and most people didn't understand what I said. I would repeat but many times before they understand, pretend to understand or give up. I think people didn't like to speak to me because it was hard for them. They don't know what to do when I stutter. I feel bad and embarrassed. Sometimes I think people even make friends with me because they feel sorry for me. I don't like that. It was easier at Medical School after I found two new friends. The work at medical school is not easy. I made it through second year and I am in my third year. The oral exams are my worst. The examiners are warned that I stutter by the coordinator. I don't tell them or anyone that I stutter. I am so scared because they have my life in their hands. I speak and answer the questions. I know the work so I do okay. I pass.

The coordinator at medical school recommended that I go to therapy. She arranged for me to have help at the hospital when I was in first year. I had to become an able doctor? I was ready to try therapy again because my speech was getting worse. I

went to the hospital for therapy. The therapist and I had a typical doctor-patient relationship. She was kind. She did the assessment and taught me fluency techniques. I used them in the clinic but could not use them outside. I just forgot. I also wasn't comfortable with the technique itself. I still thought the technique was funny. I have been at therapy for three years. It hasn't benefited me much. They only knew me as Nontokozo who stutters, nothing else. I still stutter badly even after therapy. The new therapist this year, 2001, was a bit different. She could talk to me in a more friendly way, not a typical doctor-patient relationship. She is also Black and she could speak Zulu. It made it easier to communicate with her. She seemed to understand me more as a person but she also did similar things like speech techniques. We did advertising. You had to tell people that you stutter when you met them. I hated it. It may help but I won't tell people that I stutter now. I feel stuttering is a personal thing. I don't want to tell people I stutter. They will notice when I speak. We also did mirror work but it didn't help because I don't stutter when I say words to myself. I find speech therapy boring. We did the same thing over and over again but I still attend.

On the social side I have a boyfriend, Sipiwe, who I met two years ago. I was on my way to soccer practice and we started talking. He is also a student doing project management. Yes. I play soccer for the university team. The tomboy in me? Maybe. He doesn't mind my stutter. I tell him how bad it is for me and he understands. I am very quiet and reserved and I think some people like that side of me. He is also quiet and gentle. Sometimes boys like girls who are quieter. I also like that side of me now. Had it not been for the stutter, I would be wild. Stuttering had tamed me I am happy for that. Does he see other nice things about me? Like I am friendly, academically successful, young and beautiful? That makes me blush, but maybe. We have fun together, going to the movies and the park. We are not into going to nightclubs. I stutter, not as bad and it does not trouble me much when I am with Sipiwe. When we are with other people, like at a party, I battle. I don't feel nice. I know that some people avoid talking to me because they don't understand. Sometimes they don't understand even when I repeat. I still get asked to repeat on a daily basis. It is tough. I stay silent and it deprives me of speaking. I try to be invisible and that is a terrible thing. It is terrible not being anyone.

A brighter side

The future is bright. When I am a doctor, a someone, I will be okay. I am in power as a doctor. Even now, as a student, when I work with patients I hardly stutter. My communication with patients is good. As soon as my lecturers are there it, then is a different story. I think I will be a better doctor because I stutter. I can understand what it feels like to be have a disability like being deaf or crippled. When I look at the big picture I realise that I am privileged. I stutter but I also have a very supportive family who were able to give me a better education than most Black children in the country, I have good friends, I am healthy compared to all the millions of people with AIDS and TB. I can see a brighter side for me.

CHAPTER SIX

ANALYSIS OF LIFE HISTORY DATA

In this chapter I offer an analysis of the data I represented as research stories in the previous chapter. I also supplement the discussion with verbatim transcripts from interview data. I have presented the details of how I approach the analysis in Chapter Four and therefore do not repeat these here. However, it is important to restate that the analysis I offer is one possible interpretation generated via a series of rigorous processes. I fully appreciate that I could read the data differently and that the reader might also do the same. Within the context of a study such as this one, the multiplicity of interpretations and voices is encouraged and considered a strength. Whereas the individual research stories were presented to illuminate the specific biographical experiences, in this chapter I engage with a *cross-case analysis* by adopting a strategy of constant comparison between cases, retaining the specificities of each case where necessary.

The theorising is guided by the critical questions in this study. I have chosen a *configurative stance* to the theorising process. Therefore, I weave together the many issues: biographical profiles, emotions, Significant Others, critical events, socio-cultural discourses, values, school, home and work contexts and power to explain how participants form self-identities and choose to negotiate stuttering in their life worlds over time. In the research stories, the experiences of stuttering were illuminated from multiple changing subject positions. That is, they told about their experiences from various I-positions through time and context. Multiple understandings of participants have been created, spawning a “heterogenous” self-identity through which the experience of stuttering was articulated. As a means of organising the discussion and introducing a semblance of manageability to the data, I have chosen to trace two primary self-identity formations over time. These include Self-identity as DisOther and as Self-identity as Able/Potential. These trajectories are intended as broad-based, dynamic self-identity strands forming through time. I examine how they are shaped and formed, thereby influencing how stuttering is experienced and negotiated.

The conceptualisation and “naming” of self-identity trajectories warrants explanation. The term “DisOther” refers to how stuttering as “Disorder” shapes self-identity. I

borrow this term from Pillay (2003), who uses Boehmer's (1995) explanation of the concept of "Other," referring to those who are unfamiliar and extraneous to a dominant subjectivity, appearing as opposite or negative against what an authority has defined. Applied to self-identity, I use "Other" to refer to instances and contexts when an individual manufactures *himself* as problematically different in relation to others i.e. as a relational concept. For example, as a female I may understand myself as "Other" in male company; as a child I may manufacture myself as different in adult company. The concept of Other also carries the notion of having intrinsically *less value* in a particular context. I use the prefix "Dis" specifically to refer to the instances when the individual feels "Other", as a direct consequence of his stuttering, which generates the sense of being different, under-threat, vulnerable, destabilised or disempowered. Therefore, a self-identity as DisOther means that the participant understands himself as problematically different on the basis of stuttering. I could have chosen the term "stutterer" or "PWS" but decided against this because I did not want the symptomatic appearance of stuttering to be conflated with issues of self-identity formation. An individual who stutters does not necessarily understand himself as problematically different. Also the terms "stutterer" and "PWS" have a historical baggage which might complicate the discussion.

Self-identity as DisOther within a research story is constructed from various positions, such as child in the classroom, or in the work context, at home. It is therefore intended to be a fluid construct which takes on a particular meaning within a context and across time. Gareth's experience as DisOther as a child in the classroom is different to his experience in a work context. However, both contribute to shaping his self-identity as DisOther over time. The same argument applies to the self-identity trajectory as Able/Potential. The term Able/Potential refers to the self-identities as "okay", "normal", "capable", "with ability and future potential". The multiplicities, fluidity and complexities discussed in relation to DisOther also apply.

The structure of the discussion

1. I examine the *forming of self-identity trajectories over time*. Therefore, I have arranged the analysis *chronologically* to trace how self-identities form and how stuttering is negotiated over time through three time windows viz. early childhood years, school years, and post-school years. The relationships and dominances between the trajectories are also explored.

2. Within each time period the *forces* shaping self-identity and strategies to negotiate stuttering are discussed. The forces are:

- i. Broad socio-cultural forces including political forces, social discourses and value systems.
- ii. Local contextual forces which include the immediate home, school and work contexts, critical events and Significant Others.
- iii. Biographical/Individual forces influenced by age, gender, stuttering, race, personality, motivation etc.

Although these “forces” have been separated into socio-cultural, contextual and biographical/Individual, these divisions are artificial. The forces are interlinked. I therefore *combine* the influence of these forces on self-identity formation to achieve a *configurative* understanding. There is also a discussion of the relative dominance of particular forces where applicable. The issue of power is embedded throughout the discussion, because it impacts on self-identity formations and strategies to negotiate stuttering.

3. I explore the actions of participants in negotiating stuttering over time as I trace the formations of self-identity trajectories.

The analysis therefore brings together self-identity trajectories, forces and actions over time as a basis for understanding how stuttering is experienced in lifeworlds.

6.1 Early Years (0-6 years): Variable beginnings

There are varying self-understandings which emerge in early years. For some participants the self-identity as Able/Potential is evident, while for others the beginnings of self-identity as DisOther emerge. Thabo, Nontokozo, Hennie and Siyanda begin life as “normal able” children despite the appearance of stuttering at some point in their early lives. Their self-identities begin to form primarily in home contexts in which they live as “ordinary, normal” children, who are no different to others in any problematic way. There are various explanations about why they did not experience stuttering as a problem or form a self-identity as DisOther during early childhood. There was little attention drawn to stuttering at this early stage in their home environments; a belief it would disappear; the stutter was very mild and barely noticeable; they were too young to understand it; they were included in activities as

“normal” children and stuttering was considered an attribute. Their self-identity as Able/Potential at this point is dominant and they did not experience stuttering as a problem during these early years.

Hennie: They say they hardly recognised it and I don't recall it (stuttering). In the early days life was fun. We played Glyblad, a game where the mud just flies. Yeah! we were all mates. Stuttering didn't come into the picture.

Thabo: I didn't know about it until I was at school. My mother said that I used to repeat words when I was very young - about three years - and that it will go away - just like her. I used to do things like go to the park - ordinary things like everyone else.

Nontokozi: Life was okay. I was a like the other children - playing outside, very active, very talkative. I was just a normal child. The stutter was so small, hardly noticeable.

Siyanda: I think we were born with it (stutter). No one at home said anything. It was part of us. I don't remember it. My mother says we were naughty and stubborn boys, but nothing about stuttering.

In contrast, for Sagren, Kumari and Gareth, the beginnings of self-identity formations as DisOther occur early in life. They share other similarities. Their understandings of themselves as different begin amid critical incidents at home. Kumari and Sagren begin to discover themselves as different as a consequence of their delayed speech-language development. There is concern in their home environments when they do not begin to speak at a “normal” age. Sagren's awareness is raised because he is teased by his cousins in an extended family system. He has memories of being removed from this situation by his mother who was concerned about the impact of teasing and her inability to stop it. Kumari, like Sagren, also begins to create a self-identity as different because she spoke late, at four years. There was speculation and questioning within the family about whether her difficulties were due to problems with her hearing or speech mechanisms. The initial constructions of difference, therefore, are not specific to their stuttering but their delayed speech-language development. Gareth is aware that he is different because of the direct attention to his stutter in his home context, through which he begins to understand himself as different to other people, generating a “vague” understanding of himself as DisOther.

However, their early home circumstances are complex. In each of their contexts they are also vulnerable and potentially “powerless,” sensitive children who live in the midst of difficult family situations. Kumari, in particular, attributes her silence and subsequent stutter directly to her sense of vulnerability and fearfulness as a child in an abusive environment. She explains stuttering as symptomatic manifestations of fear of her abusive father. Gareth and Sagren speculate on the causal links between their home environments and stuttering. It appears that they have a heightened

sense of being vulnerable and “at-risk”. Their “fragility” amid these difficult home environments created fertile ground to develop a self-identity as DisOther. It is possible that another child with a different personal makeup, such as their siblings, may not have been influenced in a similar way in the same situation. It is equally possible that the same child in another context might not have been as vulnerable. Hence, the combinations of the biographical and social contexts contribute to their early understandings of being vulnerable and DisOther. It would be a fruitless exercise to “compare” the shades of difference in their early experience. However, it is evident that Kumari’s early experience generates a pervasive and very deep-seated understanding of herself as Other, suggesting that these critical abuses had long-term consequences in shaping her understanding of herself as powerless.

Kumari: I never spoke until I was four. They wondered what was wrong with my hearing or mouth but it had nothing to do with that.

Gareth: I was always a stutterer... When those rows were on it was like the end of the world for a sensitive little boy like me - that made more of an impact on me than the impact of a faulting speech.

Sagren: I started speaking very late - I was over two years...I have these flashes... My father always gave my mother a very hard time...my mother pulled me by the hand... my granny opens the door.

Kumari, Gareth and Sagren come to discover themselves as different with respect to their speech through critical appraisals of difference at home. It is via *norming* processes in their homes that they discover their difference as problematic. While difference is part of everyday life, the interpretation of difference as a problem offsets their formation of self-identity as DisOther. Differences between people exist in terms of colour of eyes and hair and sexuality. Societies decide what is normal and not, based on particular values. In this instance, stuttering and delayed speech emerges as a problem, as part of a societal discourse and value system which families appropriate, and interpret (and which they in turn also shape). Norming is *value-based*. Society decides what it values as normal/desirable such as fluent speech, healthy (thin) bodies and honesty. This process is always *political*, not *neutral*. Stuttering and speech delays therefore are not neutral entities but are interpreted in particular ways. In these biographies, they take on a meaning of problem and disorder. For Kumari and Sagren it begins with concerns about them “speaking late” and what might be “wrong with them”, while for Gareth there is concern about the obvious stutter, a problem/difference which must be corrected/eliminated. Social forces in the immediate home contexts interact with the biographical specificities to produce initial understandings of themselves as DisOther.

Sagren and Gareth, however, do not have unitary essentialist understandings of themselves as DisOther. They are also normal, happy children who were part of families and communities. They create competing understandings of themselves as normal and similar to other children as they participate in games and other such childhood activities. Their self-identity formations as children who are different, and as children who are “normal and like others” appear to co-exist. Kumari, in contrast, presents a more unitary and essentialist construction of herself as DisOther, which is in contrast to what may have been observed in her outward behaviour.

Gareth: There was a lot of play... I was with my older brother and best friend...younger than them. My parents were caring. Life was good.

Sagren: I don't remember much but we still talk of the good life with the family...when we as kids would runabout...and all that stuff.

Throughout the stories the strategies participants use to negotiate stuttering are linked to their self-identity formations and shaped by how Significant Others in their environments respond to stuttering. In the early years the strategies which emerge in Gareth, Kumari and Sagren's stories reveal different ways of negotiating stuttering in their home environments. Gareth's parents intervene directly and early on and he complies. The correcting and treating in turn draw attention to his stutter, encouraging his self-identity as DisOther. Sagren's mother removes him from a threatening environment but does not intervene directly or formally, and there is no direct attention to stuttering. A similar response occurs in Kumari's story. The differences in their responses can be examined from a socio-cultural perspective.

Gareth lived in a typical middle-class white community in South African in the 1950s imbued with English norms. His upbringing is influenced by orthodox English traditions, his parents being typically English, formal and ordered. Formal (speech therapy) and informal/lay corrective practices were considered options for intervention. His parents had knowledge of speech pathology and stuttering as a categorical difference and “medical problem”. This understanding of stuttering emanates from the social discourses promoted in his white, western, middle-class community in an apartheid society. White communities were the first and exclusive recipients of speech therapy when the profession was established in South Africa in the 1940s (Beecham, 2002). Therefore, the early concern in Gareth's family is located within a broader socio-cultural terrain in which stuttering was interpreted as a problem which should be treated and corrected.

Kumari and Sagren in contrast lived in Indian communities in South Africa in the 1960s. They suggest that whilst stuttering was recognised as a problem/difference, there was little understanding of stuttering within a Western medical orientation. They attribute this to their parents being of “unsophisticated” backgrounds. Their primary strategy not to respond to stuttering in any particular way, especially during the early years. Formal intervention was not an option and was unavailable in their communities. The stories reveal that in a deliberately separated apartheid system, stuttering was recognised as a problematic difference across communities but that the understandings and responses to stuttering varied in relation to the social understandings available in these communities.

In the early years, therefore, self-identity formations unravel in varied ways across participants. For those who have self-identities as normal and able, stuttering is of little concern. However, for others, self-identity as DisOther emerges early in life as a consequence of discovering difference in childhood. The trajectory as DisOther begins as an interplay between the various biographical local (home context), sociocultural, political and biographical forces. The strategies for management are primarily driven by parents. Their responses vary from those who do not respond to stuttering in any significant way, to those who immediately seek to correct and treat the problem. However, Gareth and Sagren, in addition to their self-identities as DisOther, also develop co-existing self-identities as Able/Potential in particular contexts. As a result stuttering is of little concern in some contexts. Kumari in contrast develops a robust, resistant, unitary self-identity as DisOther in early childhood.

6.2 School Years: Multiple routes, forces and actions

6.2.1 Primary School Years: (6-12 years)

Developing, Reinforcing and negotiating Self-identity as DisOther

Siyanda and Thabo begin to form an awareness of stuttering as problematic in school via *critical incidents* in the classroom. These incidents become catalytic in creating their self-identities as DisOther. Gareth has a similar classroom experience of being “outed” which reinforces his trajectory as DisOther. Although Sagren does not experience any single event, he is teased and labelled as different in primary school, through which he displays a heightened awareness of himself as DisOther.

This strengthens his self-identity as DisOther. The events which Gareth, Thabo and Siyanda mention are clearly not events that make the Six o' clock news, and to others who were around, the event may have gone by with little notice. However, to them it was important because it served to publicize *their differences*. These are critical in shaping their lives and who they were. Participants told of these events vividly, and such events appear to have had a significant life-shaping impact on them, contributing to their understanding of themselves as DisOther.

Thabo: I was a shy and nervous boy... they all laughed and teased me because of the stutter...it was the worst moment of my life... the start of my nightmare.

Gareth: You were aware that you were different because they send around the health people... it is the worst thing to be told as a child that you are different. This small episode sticks in your head.

Kumari, in contrast, enters school feeling disempowered. Her self-identity as DisOther is *foregrounded* and remains this way throughout primary school. She is the only participant who suggests that there is no negative attention drawn to her obvious stutter at school. She explains that had this been the case she would have been further devastated, given her already damaged self-confidence. Her school was a part of the "unsophisticated" farming community in which she lived, which was significantly different from middle-class western communities. They had little "formal, medical" knowledge about stuttering. Although they recognised her stutter, they did not respond to it by correcting it and accepted it as part of who she was. Therefore, although her self-identity as DisOther remains, it is not reinforced by the responses of those in the school context but rather by her personal meaning-making. She remains disempowered with male teachers and critically self-judges by internalising a broader value system through which she understands that her speech is different and problematic, in relation to others.

Complex realities: Self-identity formations at intersections

While I have attended to the formation of self-identity trajectories specifically in relation to stuttering, and considered the combined influences of the personal social, contextual forces on identity formation, this analysis is itself reductionistic and amputational. I have illuminated one dimension of a self-identity trajectory within a complex life. While understanding stuttering in the lifeworld remains my primary interest, it is nonsensical to disregard all other complexities shaping this experience. I will use two case examples here to illustrate the complex nature of self-identity formations. This is a point I reinforce throughout the analysis.

Siyanda's early experiences of stuttering began with the classroom and playground incidents. However, he *lets life slip in* and proceeds to share other life-shaping experiences which *combine* to shape his experience of stuttering. What does one do with these "extraneous experiences" which he places at the centre of his story during childhood, in accounting for his experiences of stuttering? His self-identity occurs at multiple intersections - as a vulnerable child at home in his "broken family", as poor, a school dropout and one who stutters. His "Otherness" therefore is not constructed only on the basis of stuttering. His self-identity as DisOther is embedded within this complex reality and receives meaning within it. He feels significantly at-risk and disempowered as he negotiates varying dimensions of himself as Other, in addition to stuttering. Similarly, at a later point in Siyanda's story, race becomes a focal point around which he explains his Otherness. Kumari's self-identity as Other includes the collective influences of gender, age and stuttering. It is at these multiple intersections that self-identities form suggesting that the experience of stuttering is not simply a uniform, neat experience of disorder. It is embedded and multiply shaped by being a vulnerable and abused child, a school dropout who stutters, and a young female child who stutters under-threat in older male company. The same argument applies to Self as Able/Potential. Within this reality there cannot just be a PWS. Context and positioning are imperative.

Siyanda: We were physically, mentally, emotionally distracted... We dropped out... It was a difficult time... there was no money.

Kumari: I was always uncomfortable in male company... with male teachers, bosses, my father and father-in-law. I stutter the most in these situations.

Negotiating self-identity as DisOther

There are two broad ways in which participants who develop self-identities as DisOther negotiate stuttering during primary school years. Firstly, they choose strategies to "*normalise*" by remaining silent, concealing the stutter using a range of techniques and "*blending in*" or "*fighting back*". Secondly, they actively seek to facilitate social inclusions and acceptance. All strategies are context-dependent. Thabo and Siyanda chose to be silent in the classroom so that their problems would not be discovered. Thabo remains silent and compliant for two years to feign normality serving a self-protective function. On the playground, the repeated teasing and a severe stutter and sense of disempowerment reinforce his silence and consequently threaten the potential social relationships. He feels lonely and disconnected which reinforce his self-identity as DisOther.

Sagren and Kumari follow similar patterns in the classroom to different degrees. They use strategies of blending in and compliance to reduce attention to their stuttering, for instance being well-behaved in class and following the game without protesting. When they speak they also choose to conceal their stutter using a variety of self-taught techniques or formally-learned strategies. These fluency-inducing strategies are used with varying success. Gareth suggests that he has difficulty using them in real everyday environments, and slow and controlled speech did not suit his personality, but that any bit of fluency and any strategy to get by was welcome. Sagren and Thabo also use a combination of any spontaneous and self-learned concealing strategies to get by difficult moments. However, these strategies frequently fail to conceal the stutter, increasing their sense of disempowerment and reinforcing their DisOtherness.

Siyanda: We spoke only when answering questions and then we just sit down. We were shy guys.

Thabo: I was so hurt. I decided not to speak in class so I don't reveal my weakness. I didn't say a word for two years (in class).

The strategies of silence and concealing, blending and compliance can all broadly be explained as strategies to Pass as Normal (Goffman, 1963). Having realised their DisOtherness and the disruptive effects of stuttering, participants attempt to become "normal" as a means of creating order at the communicative interface. Silence often becomes a first and preferred strategy which can also serve as a self-protective function - preventing one from being discovered as different or abnormal. Their attempts at concealing are also a way of establishing normal fluent speech patterns and thereby passing for normal. Concealing is linked to "ordering". In situations of Dis-Order, of disruptive communication, participants conceal stuttering to establish interactional order. One way of achieving this is to feign fluency or use any strategy that creates order.

Fuelled by the threat of social rejection, they also devise strategies to facilitate *social inclusion and acceptance*. They form alliances and friendships with others with whom they feel comfortable, and in this way facilitate inclusions into social groups. This is evident in Thabo, Gareth and Kumari's stories. Sagren attempts to forge alliances by "buying" friends as a strategy for inclusion and gaining power. There are also contexts in which participants choose to stutter because the effort to conceal is great and often fails. This choice mainly occurs in situations in which participants "feel safe", trust and do not feel unfairly judged, for example with close friends, family. They suggest that people who "know them well", accept them for who they are and

are able to see beyond their stutter. This contributes to understanding themselves as Able/Potential.

In addition, Siyanda and Gareth aggressively try to *regain power* in different ways. Siyanda and his twin support each other as they both stutter. They attempt to “fight back” when they are teased to assert their power, to reveal what “they are really about”. However, given the complexity of his personal circumstances, he eventually “drops out” as a desperate strategy, unable to cope with the sense of disempowerment and disconnectedness. Gareth from early on aggressively begins to demonstrate that he is “more than a stutterer” by excelling academically at school. He remains extremely frustrated because his self-identity as a successful student is at times threatened, eclipsed and masked by his self-identity as DisOther. In an attempt to foreground his self-identity as Able/Potential, and in order to demonstrate that he is “more than just a stutterer”, he begins to *expand his biographical profile*. He becomes the team captain, excels academically and develops a talent for painting which also sets him apart from others in a positive way. There is an early and significant shift in emphasis from “What do I do about the stutter?” to “Who I become” to negotiate life and stuttering successfully.

Gareth: I was always very conscientious. I gave as good as I got. There are so many sides to one's personality - you have to seek. I performed well.

Despite the varying interpretations about what stuttering is and what causes it, from describing it as an emotional problem to the work of angry ancestors¹, stuttering is understood as a problem either in their home and/or school communities. As children who are part of their communities, they are influenced by the *dominant value-system* and social discourse and develop an understanding of stuttering as a stigmatised social problem. They “colonise” themselves as the dominant and (silent) discourses in schools and at home become their own. They discriminate against themselves by borrowing and internalising an oppressive social discourse.

Parents and Significant Others are often in *conflicting states* between accepting them for who they are as DisOther, yet wanting to make them “right” or normal for society. The first set of strategies revolves around correcting the stutter via “lay” or professional strategies and/or a tacit albeit unwilling “acceptance” of stuttering as it persists and resists correction. They tell of care, love, comfort and support as being important. They feel accepted as children setting the stage for social inclusion, as is

evident in Thabo and Siyanda's stories. As a second set of strategies, Significant Others, especially parents, also manage the stuttering on a daily basis. In addition to correcting, *disavowal occurs both at school and/or at home*. There is a "silent" acknowledgement of the problems but they are not openly discussed. All participants explained this as a particular cultural phenomenon in South Africa during that historical period when it was not common for parents or teachers to talk to children about problems. They contrast this with the current situation in South Africa (2000-2002), where the emphasis on talking about problems is being repeatedly reinforced. For instance, "Breaking the silence - talking about Aids", numerous media campaigns on talking to children about sex. Parents are encouraged to talk about stuttering.

Sagren: That's one of the strange things, Both my mother and father shouldn't like to talk about these topics... a sticky topic to talk about.

The value of disavowal is interpreted differently across or within contexts i.e. it is both useful and not useful. Sagren and Kumari in particular suggest that the lack of direct support fostered a greater sense of vulnerability and disempowerment, contributing to their DisOtherness. In the school environment, some teachers also used a strategy of disavowal and exclusion which participants respond to in different ways. Sagren, for example, suggests that teachers excluded from oral speeches which would have been difficult (for him and them) to manage. He suspects that it might have been used as a strategy by those who did not want to take the time to listen, and therefore served to isolate and reinforce his self-identity as DisOther. For others it served to draw attention (Kumari, Gareth, Hennie, Thabo) away from the problem, allowing everyday routines to continue. The classroom contexts, although varied, shared a similar general practice of "teachers speak and children listen," which did not require as much participation as would be expected in "interactive" learning environments (as currently encouraged). In such contexts, the demand for oral communication was reduced, offering less exposure to their difficulties.

Creating and reinforcing self-identity as Able/Potential

The trajectory as DisOther competes with the trajectory as Able/Potential to provide a further complexity to the experience. Gareth is a competitive child, a team leader and an excellent academic, for which he receives awards and public recognition. Siyanda understands himself as able and with potential in a home environment where he is supported by his mother and encouraged to explore his abilities. Similar competing

¹ Angry ancestors: describing a belief that is of Zulu heritage.

constructions of being Able/Potential begin to emerge in Sagren and Thabo's stories. Their self-identity formations change across situations, contexts and relationships, and therefore their experiences of stuttering are varied.

Nontokozo and Hennie's trajectories as Able/Potential continue through their primary school years. They are aware of their stutter, but they remain unconcerned. Hennie emphasises that his upbringing foregrounded religious and cultural values linked to being an Afrikaner. Stuttering, however, was not unnoticed because his parents together with teachers arranged for him to attend speech therapy to treat his lisp and stuttering. However he did not develop an internalised understanding of himself as DisOther. His Self-identity as Able/Potential remains foregrounded and robust. He is friendly, congenial nature, participates in sport and leadership activities.

Hennie: Parents emphasised "normal things like becoming an Afrikaner, knowing your history and how to be a good Christian". I was in rugby, athletics and prefect ... people saw more than the stuttering... I never let it rule my life.

The creation of self-identities as Able/Potential are encouraged at an early age by Significant Others i.e. they should Become Someone. Parents, teachers, uncles, aunts and grandmothers assist with creating potential for who they should become without a singular focus on stuttering. They understand participants as "more than just stutterers". Sagren is inspired by an early comment dropped by his mother when she suggests that he has potential to become a teacher, at the time (late 1980s) a well-respected profession within the Indian community. Gareth is encouraged to be competitive in a school environment so that he can be a successful professional. His father carefully tracks his progress and he remains conscientious in an effort to fulfil the expectations in a competitive environment. Kumari is encouraged to become professional but also to become a wife and mother. Siyanda similarly receives advice from his mother to return to school because education was of key importance to Becoming Someone. Siyanda's mother responds to them as equals and in constructing stuttering as an attribute (a feature of who they are) they are supported because they are treated as equal (children). Siyanda reinforces the point that they were not judged as "less than" others by their mother and this stance had an enduring and influential influence on his self-construction as able.

Gareth: My father had already decided that I was going to do architecture.

Kumari: My mother wanted us to have a better life, to be educated, have good jobs.

Siyanda: She explained how important education is... she made us to see the need and necessity for education... 'cos it is the only way to succeed.

Sagren: My mother was standing nearby and she said "Why don't you become a teacher. I think that you will do quite well." I can still remember that comment she passed me...

However, the emphasis on "becoming someone" is part of a cultural tradition of "normalising". It is also influenced by the political environment at a given time in South Africa. Hennie and Gareth's stories unfold in different decades and within their particular white, middle-class communities there was an assumption that they would complete school and proceed to university. Their families actively help to create their futures as educated professionals. Sagren, Kumari, Thabo, Siyanda and Nontokozo are also actively guided on a path to Becoming Someone. Kumari and Sagren are from Indian communities which were actively aspiring to become upwardly mobile during the seventies and eighties. Their lives are embedded within communities aspiring towards the "better life" of the economically powerful, educated, white communities (Desai, 2000). Thabo and Nontokozo are both of black communities but of different economic circumstances. The importance of good education and "Becoming Someone" occurs at a crucial time in the country's history and are influential in their biographies. Black families were aware that they could access university education in a system which was rapidly changing. Thabo and Nontokozo change schools specifically to achieve this end and are actively guided towards a better future. Siyanda, in contrast, does not have access to economic resources, but his mother's advice is to get an education as a means of accessing a better life. Becoming Someone therefore is influenced by the dynamics of the social climate. Importantly, in these stories their self-identities as *Able/potential are encouraged, despite stuttering*.

Summary: Primary School Years

In primary school years, it is evident that participants continue to form their self-identities as DisOther, as a consequence of many forces. The stutter persists, and they develop an understanding of its disruptive potential at the communicative interface and become self-aware and critical. However, it is also apparent that the contextual forces, including critical events at school in particular, shape their identities as DisOther. The embedded value system is society available in local contexts especially schools and homes encouraging "orderliness" and "normality". The understanding of stuttering as a problematic difference reinforces the formation of their self-identity trajectory as DisOther. Participants choose strategies to negotiate stuttering which are strongly guided by their particular contexts. These

include concealing, negotiating social inclusions and regaining power. Although self-identities as DisOther become prominent, there is also the beginning or strengthening of the trajectory of Able/Potential, which serves to compete or co-exist with self-identity as DisOther, as evidenced particularly in Gareth's story. The responses of parents and Significant Others are important in two ways. Firstly, the strategy of disavowal in response to stuttering is dominant across stories whilst participants' responses to this strategy are characterised by ambivalence. Correcting speech serves to further reinforce the formation of DisOtherness because it attends to an attribute of speech which resists correction. Secondly, although the stutter prevails, Significant Others simultaneously lay the foundation for creating a self-identity as Able/Potential.

6.2.2 High School Years (12-18 years)

Later beginnings of self-identity as DisOther

Hennie and Nontokozo do not experience stuttering as a problem until high school. Here I focus on how and why they develop self-identities as DisOther. Having completed primary school in Umlazi, Nontokozo attends a new high school selected by her parents. They believe that she should receive a good education which was not available in the Black township schools. They send her and her siblings to a Convent boarding school in KwaZulu-Natal and it is in this specific context where she begins to form an self-identity as DisOther. Upon entry into an alien environment, Nontokozo feels extremely threatened and this creates fertile ground for the *stutter to grow i.e.* the symptomatic presentation becomes severe. Her sense of feeling vulnerable and Other occurs as a consequence of many changes upon entry to school. In the midst of these difficulties her stutter becomes very severe. Through these various happenings she begins to construct herself as DisOther.

What changes for Nontokozo?

From exuberant tomboy to a little lady in an all girl school

From a system of relaxed rules to a system of very strict, rigid rules

From talkativeness to silence

From Zulu-speaking to English-speaking

From academic familiarity to academic unfamiliarity

From Zulu-speaking Black teachers to English-speaking White German teachers-strict nuns

From the comfort of home to a new and threatening environment

She also attends therapy for the first time and this confirms that stuttering is a problem in a formal way.

Her stutter becomes severe

Biographical suicide (Samuel, 1998) best describes her experience as she is expected to “leave herself at the door”. This is a devaluing of one’s history by obliterating oneself. She is expected to take on the values of a powerful and dominant new system, alien to her. However, her “not knowing”, discomfort and uncertainty are accompanied by a pressure of feeling “less than” and disempowered, as she has to create a new self-identity. The thoroughfare between the body/impairment, Self and society in shaping her experience receives clear illumination here. The events in her social context influence how she feels and who she feels which in turn influences the symptomatic presentation of stuttering which in turn influences how she feels and understands herself - the interpenetrations continue and her experience is fashioned in the midst of such complexity.

Nontokozo: We were taught English by White people and all the stuff was new. I had to go to the school but I didn't want to... it was strict...

Hennie attends an Afrikaans high school. Unlike Nontokozo, he is familiar with the pupils and teachers but begins to grow concerned about his “difference” at a time when, as adolescents, they begin to explore their identities. Hennie appropriates broader normative social discourses to understand what is normal and what is not. Stuttering is abnormal. Against this understanding he judges himself as different and DisOther. He rapidly becomes frustrated with himself as he finds that he is unable to change his speech patterns when it matters most. It is through processes of comparison with others and questioning of his identity that he begins to accelerate and reinforce his understanding of himself as DisOther. He rapidly internalises his new self-identity which is in conflict with his self-identity as Able/Potential. Like Nontokozo, despite knowing of the symptomatic features of stuttering during primary school, he only begins to form a self-identity as DisOther during high school through a combination of social and personal processes.

Hennie: At the end of standard six I realise that my stuttering is bad and it has been hampering my life. Maybe it was adolescence... that age you know... when you realise now you are getting on with your life you know... evolving.

Sedimenting Self-identity as DisOther

Like Nontokozo and Hennie, for whom high school presents new challenges, Thabo remains sensitive and shy when he moves to a completely new area to live with his aunt amid the political turmoil in his area. He has initial difficulties adjusting to new people given his severe stutter and construction of himself as DisOther, reinforced by the responses of others at school (although these are more subtle at this point). Gareth, sensitive and younger than the rest, enters into an increasingly competitive environment of high school with strict rules. He continues to stutter, which reinforces his identity trajectory as DisOther. Sagren and Kumari's transition into high school is uneventful but they continue to remain lonely and isolated.

Thabo, Gareth and Sagren's self-identity as DisOther is reinforced and becomes a dominant/foregrounded self-construction during high school years. The stutter remains severe in some instances and resistant to change. They judge themselves severely, and regard themselves as "less-than" especially when their difficulties are most prominent during classroom oral work, which is a formal expectation in the curriculum. Their self-identity formations as DisOther are strengthened as a consequence of being *judged and evaluated* by teachers, peers and themselves when they are required to read or deliver speeches. They continue to use self-taught strategies to reduce the stutter but remain unsuccessful. Their "failure" to induce fluent speech further sediments their DisOtherness because they realise that the stutter is chronic and relentless and frequently resists correction. Their frustration is heightened especially in the classroom context as their Able/Potential selves remain *in tension and conflict* with Self as DisOther, and often eclipses their identity as Able/Potential.

Social Inscriptions: Schools and professional authorisations of difference

The school as context is significant in shaping experience and I therefore single it out as a specific and prominent contextual force which influences self-identity formation as DisOther. Participants have spent a minimum of twelve years at school. Their self-identity as DisOther is reinforced by negative experiences which include:

- ◆ Identifying and authorising one as different
- ◆ Judging, evaluating and teasing within the school community

- ◆ Negative evaluations by teachers and “low marks” for oral work
- ◆ Referring for assistance by school authorities

The school is an *arm of society* in which stuttering continues to be *socially-inscribed* as a problem. In a Foucauldian (1977) tradition, the school, among its other functions, also performs the task of surveillance via processes of scanning and detecting - it identifies problems like stuttering. In cataloguing difference, it draws attention to a “pathological/abnormal” dimension as part of a broader social function. As a symbol of authority, the school has named and authorised the problem. While it may be argued that these processes serve in the interests of helping children, the stories also reveal how they simultaneously foreground problems by formalising, authorising, judging and evaluating, thereby generating heightened awareness of norm deviations. In this regard, the school transmits and sustains a dominant social discourse of stuttering as a problem. At the same time, however, school is a site where participants establish their potential selves and begin to create futures within society. Having a good education and promoting cultural values through sport, offer participants the opportunity to create their potential and foster their “normality” and inclusion.

In Nontokozo, Gareth and Hennie’s stories *schools collaborate with professionals* to treat stuttering. Whilst professional intervention is a means of helping the pupil, it also serves to cast stuttering formally into the realm of disorder and reinforces DisOtherness through various professional processes. As Thabo aptly states, “it is where they will ask *What is wrong with you?*” Participants have a problem for which there is an official and formal mechanism for treatment. Professional interventions are social processes which filter into schools, homes and communities which have potential to reinforce DisOtherness. It is in these particular contexts that they become DisOther because they are constituted as “patients or stutterers” in a context in which there is specific emphasis on disorder and treating it.

Gareth: She tried to help but I hated it because it intruded on all the joys... my sport and all that stuff... I was just fed up with it... just relax, relax... it didn't do me any good.

Expanding Biographies and strategies

During high school participants expand their biographies and continue to create potential selves utilising their *resources/assets*. Thabo realises that he is academically talented later in high school. He feels empowered particularly in

contexts where he has a good knowledge base. In these situations he foregrounds himself as able and with potential, as this trajectory competes with self-identity as DisOther. Sagren and Gareth have similar experiences. Furthermore, all participants except Kumari choose to participate in sport as a means of facilitating social inclusions and thus expanding their biographies. Sport in all schools and communities is encouraged and celebrated. An individual who is successful at sport is a cultural "hero". Nontokozo's participation in sport occurs for similar reasons as for others but is also a means of regaining her (exuberant) self. Gareth and Hennie also occupy leadership positions through which they feel empowered, at least temporarily. When self-identity as Able/Potential becomes dominant in particular contexts, that is, when a person has better knowledge of a particular topic, he also reports an accompanying decline in the symptomatic appearance of stuttering (Gareth, Thabo, Sagren) and a general feeling of "being in control".

Thabo: I was good in biology and geography and everyone was expecting my help. It was easy for me. I was now given a chance to prove myself by communicating with other children... to prove that I was like other children... it was better... but there was no serious change in my speech.

Hennie: I was in matric... the Sergeant major in the marching band... I was popular... I was a prefect.

Gareth: I had done all the work and I could do it better than anyone else... I was in the local soccer team.

During the high school years Significant Others realise that participants continue to stutter, that is, the stutter has persisted over time and they respond in varied ways. Hennie and Gareth attend speech therapy from which neither of them benefit in the long-term, for various reasons. Kumari's mother actively seeks help in the form of speech and drama. Responses of supportive teachers in high school are evident in Thabo and Gareth's stories. Thabo explains that some teachers were aware of his stutter. They offered comfort and support and they were flexible with their demands. They were also able to recognise his academic potential despite his stutter and encouraged him to teach others. While he finds the task of teaching others threatening because it parades his DisOtherness, it also serves to set him apart as academically able in a positive way. Gareth tells about the teacher who assisted by offering him choices in a context in which he feels most vulnerable. Gareth explains that he would have been devastated if he stuttered and "failed" in an extremely competitive environment. He chose not to participate and felt that being forced to participate under those circumstances would have been devastating for him.

Kumari and Siyanda's experiences change course during high school years in comparison with their primary years. Kumari expands her biography differently to

others because she learns how to conceal her stutter by making slight adjustments to her speech. However, although she is fluent and overtly “able” she remains disempowered and has a low self-worth, poor self-esteem and is lonely/disconnected despite being in company with others at school. Her fluency becomes a fragile façade which masks her self-identity as DisOther. Having re-entered high school, Siyanda remains quiet and disempowered. However, he begins to facilitate his inclusion into school activities. A critical incident, “the audition”, becomes the *turning point* at which he begins to strengthen his trajectory as Able/Potential. Through this incident, and events that follow he realises that he can enhance his communication, that there is potential to change (and be more fluent). In his story improved fluency creates the initial impetus for forming a self-identity as Able/Potential. Through his friend, he is able to access his resources and strength and creates his future Potential self-identity. He actively pursues the development of skills and takes on leadership roles as he feels more enabled and self-confident. Through these efforts, his DisOther trajectory becomes less prominent as he begins to shift his self-definition from a disabling to an enabling discourse. As a consequence, his experience of stuttering becomes less problematic.

Genesis of Self-identity as DisOther: Summary

By the end of their school careers participants develop self-identities as DisOther through multiple forces and processes. Although I have foregrounded the social forces in the stories, their self-identities are also influenced by their personal experiences of stuttering as a phenomenon. I have not presented detailed analytical commentary on this aspect primarily because they have been illuminated in other studies (Sue-O'Brien, 1993, Corcoran & Stewart 1998). However, because the personal meaning-making of their experiences of stuttering as a phenomenon reinforces their identity as DisOther, I have included a summary analysis in Appendix Q. These experiences include: feeling of uncertainty and loss of control over their speech mechanisms, extended moments of suffering; communication-in-jeopardy and burdening relationships, a constellation of negative emotions and evaluations and being the “odd-one-out” with a puzzling problem.

The genesis of self-identity as DisOther occurs via a combination of social and personal processes through which participants come to understand themselves as DisOther. DisOtherness is disempowering because it is a reductionist, deficit-oriented construction. “I have a stutter”, through various social/personal processes over time,

is translated into "I am a stutterer" leading to a feeling of being different and less-than, which threatens one's social acceptance and self-potential. However, one might argue that while society may construct stuttering as a problem, participants are equally to "blame" because they also construct stuttering as a problem. The *personal, social separations are artificial* and raise a fundamental issue about the relationship between the individual and society. In an unsettled debate I take Bauman's (2001) position about interpenetrations of individual and social. Society and Self are mutually-constitutive. Therefore, it is not unusual that individuals share the same value system as society in creating stuttering as a problem and using a deficit-orientation to construct, judge and reinforce themselves as DisOther. *They contribute to the creation of their own oppression* (often without realising this). It is taken for granted in society that stuttering is a disorder/abnormality - it takes on a "natural" meaning as a "disorder".

In the stories there is also a sense of *anger* which emerges which suggests that the creation of DisOtherness *is unfair and unjust*. For Siyanda, it is Unfair because he is being punished for something he has no control over; for Sagren and Gareth, it is Unfair making a public display and the labelling and teasing neglects and masks aspects of their identities as high-achieving boys; for Thabo it is Unfair because he is being ridiculed for something he does not willingly do and because it is for something he cannot change - it just happens. For Kumari, oppression and ruthless authority is Unfair and therefore stuttering (at a point in her story), is symptomatic of injustice and fear.

The temporal dimension is also important. The identity formations begin and change variably over time. While self-identity as DisOther is shaped, reinforced and sedimented over time, it also seems that a single event can create an internalised understanding of oneself as DisOther. *I have, I am, I am less-than* occur simultaneously for some (Thabo and Kumari). For others (Sagren and Siyanda), a series of processes over time shape identity as DisOther.

In the school years, although the self-identities as DisOther and Able/Potential continue to form, self-identity as DisOther appears to dominate. The contexts shaping self-identity include home and school, the participants share a common dominant discourse that stuttering is a problem. As a summarising strategy to explain the genesis of the self-identity trajectory as DisOther during childhood years and extending into adult years, I present a diagrammatic summary (Figure 3).

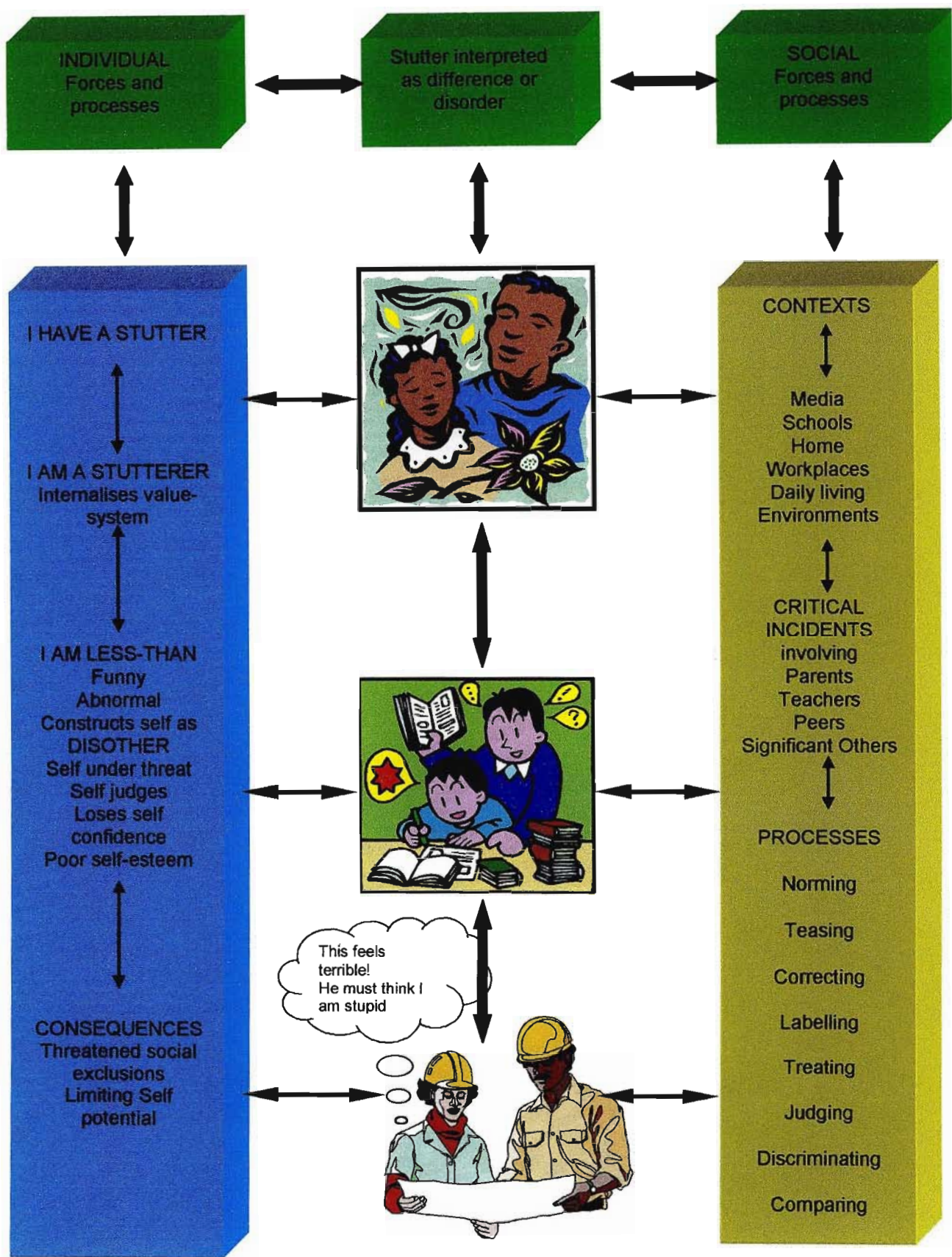


Fig. 3: Genesis of Self-Identity as DisOther

6.3 Post-School Years

In this section I cluster the biographies into two groups: Firstly, those who foreground identity formations as Able/Potential (Siyanda, Kumari, Gareth and Sagren) and negotiate stuttering successfully and secondly, those who foreground their self-identity as DisOther (Thabo, Hennie and Nontokozo) in post-school years. I attend to the particularities of each biography because they are shaped in unique ways. The forces shaping self-identity formation and the strategies used are traced within each biography. I also comment on the similarities and differences across the clusters. The discussion for those who live successfully revolves around one theme: On becoming Someone: strengthening and foregrounding self-identity as Able/Potential. The forces, contexts and actions of those who continue to foreground their self-identity formations as DisOther are also examined. I begin the discussion by presenting the specificities of each case to explain how and why they form and strengthen self-identities as Able/Potential. The critical periods, events, and actions taken to negotiate stuttering are explored.

6.3.1 On Becoming Someone: Strengthening and foregrounding self-identity as Able/Potential

In the silent world, in the shadow world, there are always people dreaming of changing the configuration (Okri, 1997)

6.3.1.1 Siyanda's theme: Reframing yourself and dreaming possibilities

"I think it's the focus, the vision... I have invested in my dream..."

There are two *critical happenings* which create the impetus for Siyanda to strengthen his self-identity as Able/Potential. After the first critical turning point in high school and his involvement in drama, he learns assertiveness skills and skills to enhance his communication. Feeling more confident, he actively creates a Drama Society in school and takes on leadership positions through which he begins to feel empowered. As he strengthens his self-identity, he is encouraged by the positive evaluations he receives in his school context. As a consequence, he begins to participate in activities which reinforce his sense of belonging, acceptance and inclusion. Although he continues to stutter, he develops skills to conceal his stutter partly on stage, and experiments with integrating his stutter into his unique stage

style. However, his trajectory as Able/Potential does not unfold evenly as his life takes a downward spiral when he fails matric and is not able to pursue his dream of going to university and becoming a teacher. Instead he takes on a job in which he feels extremely frustrated, and oppressed, once again foregrounding his self-identity as one who is not progressing. After the second *critical incident*, "the assault", which he interprets as a sign from his ancestors that his life was moving in the wrong direction, he begins to reflect on his *future and the grander issues of his purpose on earth*. He makes a life-changing decision to create his future as a community educator having witnessed and experienced the problems of a socially oppressed-community in apartheid times. "*The ancestors were driving me away from there...I had to do my performances... my soul was in peace because I did what I had to do.*"

Why is this decision significant, and how does it relate to his experience of stuttering? Siyanda presents this decision as a pivotal one because he has created and strengthened the possibility of a future Able/Potential trajectory that he actively pursues. In creating a dream he also creates a *potential* which he has to activate. He imagines a future Self constructed within an enabling discourse. In simple terms, he cannot be that "Someone" if he continues to frame himself within a deficiating discourse as poor, black and a stutterer. However, strengthening his self-identity requires practical action. He forms his own organisation as a vehicle to achieve this, establishing himself as the director of his Drama company, a dream which to many people seems irrational.

However, becoming Able/Potential is constantly shaped and influenced by life events which he must negotiate. There are a series of critical issues (unrelated to stuttering), through which Siyanda also learns about his Otherness during adulthood. As he interacts with people from other race groups in an apartheid era (1980s) he discovers that his English is not very good. He has direct experiences of racial discrimination, and becomes acutely aware of his lack of formal education and restricted finances. These issues become prominent and centred in adulthood. While stuttering remains of concern, it is embedded among other more prominent concerns. I use the concept of "changing centres and margins" to suggest that at different points and contexts, different issues (race, language, economic status and stuttering) become prominent. They are dynamic and interactive and shape his self-understanding and his choices and actions.

Being black, poor and speaking English as a second language are only meaningful within a particular *socio-historical context*. These do not create Otherness within his community, where he is like everyone else. In an apartheid society, being black in South Africa at the time was interpreted as being “less than” (White, Indian and Coloured); English was valued while African languages were devalued. Therefore, if one did not have the valued social profile, one felt devalued. Creating oneself as Able/Potential therefore involves negotiating a multiplicity of dimensions such as race, language status, stuttering, economic status. Within this context how does Siyanda create an understanding of himself as Able/Potential?

Reframing becomes an ideological tool by which he continually recreates and strengthens his self-identity as Potential/Able. Importantly, this shaping occurs in a rapidly changing socio-political landscape impacting on his self-identity formation. As a consequence of his participation in political activity, Siyanda is sensitised to the emerging activist discourses during the 1980s. He becomes instrumental in promoting a new discourse in his community which challenges the oppressive ideologies of the apartheid regime and generates a new celebratory discourse about black people using concepts of the African Renaissance and Ubuntu (togetherness and brotherhood) as enabling ideologies. Siyanda imports these concepts to challenge traditional notions of what “black” could mean. He reframes the notion of black within an enabling discourse and then appropriates the same discourse to challenge how stuttering has been constructed. He argues that as “black” had once been understood in deficit terms within discriminatory, categorical rhetoric, so too has stuttering. In being able to reframe black as beautiful he asks “*Can the same not apply to stuttering?*” He argues that it is possible to rethink stuttering as something “beautiful,” as an attribute that contributes to a unique, special and able someone who speaks with a particular style. “*I am just a blessed guy to have a stutter, to be a Black guy, to be what I am... I strongly believe that my culture is unique to me and yours unique to you...I am proud of who I am.*”

Why is reframing and creating Able/Potential self-identity important? Siyanda suggests that the deficitting discourse is only about what you are not, and there is little you can do about that. It is a discourse which paralyses and disempowers the Self. “*When you feel disempowered and disconnected on the inside you interact with the world like a loser*”. You reflect your disempowerment by acting it. In contrast, an asset-based discourse creates potential and possibility to Become Someone. Importantly, his self-identity as DisOther is available, but is reconstructed and

reconciles with this self-identity as Able/Potential. This self-identity as one who stutters, therefore receives “acceptance” with a new understanding of “normal”. It becomes possible then to be successful and stutter. *“I can also be normal and stutter”*

Reframing oneself within an asset-based discourse in itself does not resolve all his problems. The world remains essentially political and the power differentials between rich-poor, black-white must still be negotiated. The individual must contend with old, new and competing value systems. Racism did not die when the new government was established. Although the political climate is changing, the old is never completely replaced with the new and therefore it is in the midst of these discourses that one is always in the process of creating oneself. Although Siyanda pursues a self-identity trajectory as Able/Potential (*“I am the torchbearer”*), there is recognition that it needs constant resourcing and retooling. To this end he brings many personal resources. I discuss three primary strategies.

At the communicative interface Siyanda actively *negotiates power* dynamics to reinforce his position as Able/Potential. He recognises that he must negotiate various dimensions of Otherness to foreground his self-identity as Able/Potential. He views communication as a collaborative process and argues that collaborations are only possible when there is a “balancing of power”. He actively attempts to equalise power. For example, when with people of formal educational backgrounds, he negotiates a “levelling and equalising” of power by presenting himself as different but equal. To this end he “peels the layers” off race, education, language and class to establish a common ground - so that we can interact as people and as equal. *“God is playing a puzzle and every person has a piece to play... A partnership needs us to be equal...the levelling...There must be power for each.”* He acknowledges that there will always be differences but suggests that how we interpret the difference is important. In this regard, he usually chooses not to conceal his stutter but to reveal it as an attribute unique to him. He therefore negotiates communication as an equal *with a stutter*. He continually extends his skills and knowledge base to place himself at an advantage by “knowing”.

Siyanda is also a social being. He is happiest when he is with people and doing what feels right for him i.e. community education. *“It is not just being confident...it is more than that...it is composure... This means knowing I am doing the right thing for my people...”* Being in the world with people requires *social skills* which he actively

develops over time and this contributes to the strengthening of his self-identity as able. He presents himself as entertaining, charismatic, knowledgeable and likeable with his stutter and is therefore chosen as spokesperson for community functions. While most people know that he stutters, and it has become a defining feature of a part of who he is, and unproblematic, given his social skills repertoire. He communicates successfully with a stutter.

Siyanda lives in a political world with people who do not necessarily share his worldview. Part of the strategy to strengthen his self-identity as Able/Potential includes his ability to *negotiate a critical lifeworld*. On occasion he receives negative reactions which draw attention to his stutter or race. He negotiates such responses with seeming “non-action”. He shifts his attention away from the stutter to examining the values of those who “judge” him. He explains that when a person sees him as a stutterer, they are looking at a part of him that is different to themselves. “*They have picked on that attribute that makes me different to them... If they want to laugh or ridicule me on the basis of my difference... the colour of my skin, or my stutter... because I am not like them... then it says more about them... about their prejudices than about who I am... That’s their problem...*” He chooses to ignore their responses.

I summarise his strategy for strengthening his self-identity as Able/Potential by borrowing from the idea of *sociological imagination* (Mills, 1959). An individual with “sociological imagination” understands his circumstances against a larger historical context. Siyanda is able to reflect on his experience within a historical period, and is able to link his history and biography. He grasps the broad societal issues of oppression and discrimination which shape his experience. In this way he becomes the social analyst of his own situation. He understands his experience as an intersection between his historical self and society. Within this frame he is able to understand and question how and why his self-identities form in particular ways, that is why black skin and stuttering are understood in particular ways in society at a given time. His imagination allows him to shift perspective, to view himself from political and psychological-emotional domains and to understand the links between power and emotion within his story.

Having inspired himself through new discourses and taken on a different set of values, he becomes transgressive/transformative. In situating personal issues within the public domain his personal troubles do not remain “private” and of his own doing. Stuttering and race are not merely problems belonging to individuals. He is actively

able to contest traditional values in society using current political ideologies and applies the benefits of such learning to creating his future potential. He makes a case for stuttering and race to be understood as difference on a continuum of diversity rather than as pathology rooted in traditional categories of adversity. He dreams and imagines future, potential and possible selves. While the politics of daily life must be negotiated, he is also guided by the many discourses of hope, creativity, collaboration and connections with spirit, to fashion a dream of Becoming Someone.

Why does Siyanda's story unravel in this way? Is it because he lives at a time when there is a changing discourse which he can appropriate? Is it because he has an agentic streak? If so, where does it come from? Combinations? He lives in a time of turmoil where there are also new social discourses which encourage and renew personal possibilities, hence the social becomes personal. He has a "fighting/resilient spirit" as he fights against oppression with children on the playground, with his father, against apartheid. He accesses spiritual power and feels guided by his ancestors. In an information age "knowledge is power", he strengthens himself by being knowledgeable. Comparing him to his brother who shares a similar biographical profile, what makes him different? *"I have a dream and I make choices to make that dream come true"*. A unique combination of personal and social forces shapes his self-identity formation as Able/Potential.

Against this background Siyanda regards stuttering as a non-issue and negotiates communication by stuttering openly, and occasionally taking pragmatic decisions to conceal his stutter. His self-identity as Able/Potential with a stutter remains robust as he continues to fashion himself within an enabling discourse.

6.3.1.2 Kumari's theme: Rebuilding yourself inside-out

Kumari remains DisOther and disempowered for most of her adult life despite her fluent speech. She accesses all the "appropriate" social processes as a means of shaping her social career during adulthood. She graduates with a university degree, enters the world of work, gets married and becomes a mother as a means of forming an identity as able, but is largely unsuccessful. She continues to remain disempowered in the company of male authority at work and at home. Having discovered that her young son stutters, she is forced to reopen her dialogue about stuttering (which is safely hidden). During the seven years he attends therapy she becomes both hopeful and despairing: hopeful that he will retain his exuberance and

become the famous car designer he role-plays repeatedly, and despairing because the stutter remains. In contrasting and comparing their lives it becomes clear to her that her own disempowerment and slavish need to please society drives her untiringly to get rid of his stutter. It is this critical experience which prompts her to become self-reflexive as she “diagnoses” her own (masked) but deeply-embedded DisOtherness and actively seeks ways of helping herself and her son.

The strategies for creating her self-identity as Able/Potential have a gradual beginning through conversations with her “disabled” relative, who inspires her into believing that everyone has potential and possesses a divine spirit, and that it is possible to regenerate one’s self. She explores the links between mind-body-spirit-emotions as a means of developing herself, and, within this exploration she tries to understand stuttering. She is convinced that she can achieve her potential by building an empty spiritual self *inside-out*. However, she finds the spiritual teachings vague and abstract. Through her husband, who accompanies her on a spiritual journey, she attends a course which provides her with the necessary skills to activate her learning potential. Here she discovers the power of the mind in shaping oneself in a positive way.

Through active and religious application of these skills, she is able to recreate herself as Able/Potential. As a consequence, she develops the skills base to interact with teachings about spirituality. She reads many books on self-development and spirituality through which she *re-educates* herself. Through these and other religious activities, she is able to understand spiritual dimensions of Self and continues to rebuild her self-identity as Able/Potential from inside-out. However, even as she strengthens her self-identity as Able/Potential, she continues to struggle with ongoing prejudice (including her own) about stuttering.

She maintains her curiosity as she continues to question how stuttering occurs and wants to understand how fear, an emotion, could be enacted at a cellular level and create a condition like stuttering. Her search leads her to a different set of readings which explain how one’s biography translates into biology. This holds some answers to her question. She questions how fear, arising from a traumatic incident can disrupt cellular programming and the possibility of reversing this process. Her “Journey” process requires that she find her “*authentic self*,” a self with boundless spirit, an “infinite intelligence” at an emotional level, untainted by the confusions of the mind. She comes to regard this Self as her Able/Potential self. However, in order to restore

this authentic Self she has to “journey back” to a point in her history where her emotions were blocked and infused at a cellular level creating stuttering. The emotional/spiritual release process requires forgiveness, to “Let Go” of things in the past, and set her spirit free “*You must do this to become your authentic self*”. Kumari remains convinced that her Able/Potential self or “*authentic self*” should come out of a process of spiritual growth which would “resolve” the fears and blocks which have created stuttering.

She makes the journey from victim to victor begin in a particular way during adulthood. Why? Is it because of her status as a woman, her beliefs or the culture in which she lives? Kumari had opportunities to access and appropriate social power by getting a degree, a job, and becoming a mother. Yet all of these “things on the outside”, the social trappings, did not empower her sufficiently to create herself as Able/Potential. Is it because she is a woman and unable to feel empowered in a man’s world? It is one possible interpretation. Kumari, unlike the other (male) participants does not gain power within a social structure that is designed to privilege males. She interprets the world as gendered and unequal. Her father reigns in a paternalistic guise and in his presence she is powerless. She feels under-threat at school with male teachers, and at work where she cannot negotiate male bosses as equal. When married, her husband becomes the dominant male figure, as she learns to take on a submissive role.

Does her strategy come of her belief that her emotional/psychological damage had to be healed to Become Someone? Kumari steadfastly believes that the cause of her disempowerment and stutter was an emotional block for which she must find release to Become Someone. Where did this belief begin? And why does it remain so Herculean? She suggests that her biographical experience, the feelings she felt at the time of abuse, were so intense that they became foundational in trying to make sense of her stutter. Although she understands and questions biomedical descriptions of stuttering, she does not find them meaningful in making sense of her own experience. She remains faithful to her belief and finds alternative theories to mainstream, to reflect on herself. She suggests that “*our purpose on earth is to understand who we are.*” Although her reasons for why she stutters change and evolve, from one of oppression to an act of karma, it remains rooted within her reflexive realm of experience.

Kumari's journey into self-discovery occurs at a time in history when Self-development is strongly promoted in the media in South Africa and internationally. Television programmes such as Oprah have run over the past four years (1999 - 2003) the series on Soul Stories (Zukav, 2000), and Self Matters (McGraw, 2001) to name a few. Kumari has accessed a range of popular literature on Self-development. Within this culture the need to become your "authentic self" (McGraw, 2001) and "find your spirit" (Oprah) are common discourses. These self-development discourses promote living successfully with any problem. Within this frame, the biomedical plot has received a strong challenge from those with long-term, incurable and puzzling diseases and disorders. A new talk of self-healing, hope and courage has flourished. Kumari lives within this cultural world, and accesses these discourses as part of her journey to Becoming Someone.

6.3.1.3 Gareth and Sagren's Theme: Creating social advantage: manipulation of power

Although Gareth and Sagren have different life experiences, there are resonances in how their self-identities as Able/Potential are formed during their adult years. I therefore cluster the analysis of their experiences. The strengthening of their trajectories as Able/Potential begins during childhood and continues throughout their lives. Sagren's impetus for creating a new self-identity comes through a critical event at work. As a consequence, he attends a self-development course, a turning point at which he begins to create an understanding of himself as Able/Potential. For Gareth, the transition process is more gradual and unfolds via a series of events spread over many years. Both aspire to becoming professional and family men, which contribute to their profiles as Able/Potential. Serendipity plays a role as they begin their careers in supported environments. During this period, their biographies as professional and able people are quickly established and expanded.

They settle into a professional world, but face difficulties because professionalism demands good communication as a sign of knowledge. In these contexts the Self as DisOther and Potential compete for dominance. They negotiate these situations in pragmatic ways which help them to survive difficult situations while still trying to project positive self-images. Gareth relies on his partners for support and accentuates his ability through his drawings. They both learn social, conversational skills which allow them to actively engage socially and facilitate their inclusion in a range of situations. They develop a skills-base to enhance their social

communication. They know what works and what doesn't work for them at the communicative interface, as they revise strategies continuously. They resource themselves so that they can strategically manipulate the balance of power in their favour using a variety of skills, such as beginning conversations with jokes, "reading" the interaction and context, preparing in advance and taking charge of the interaction.

In the work context, they remain upwardly-socially mobile within their professional and social careers. They expand their biographies differently but with the intention to climb "professional ladders". Gareth establishes himself as a partner in a successful architecture practice which grows in stature, while Sagren is rapidly promoted. Their profiles as "able" expand during their 20-30s. Their primary strategy is to create Able/Potential selves by gaining power through knowledge: by knowing people, information, social skills. Sagren explains, *"when you know something that they don't, you have control and they will wait through the stutter to hear what you have to say"*. Gareth uses a similar strategy when under threat, as he explains in his interaction with "Smarty Pants": *"I will talk over his head and that will floor him."* When under threat, therefore, they seek to manipulate power in their favour. Their strategy therefore shifts from changing their stutter or attending to it, to one in which they actively negotiate power within relationships to their advantage. They create this advantage by being powerful men with social skill and from this position, stuttering is of minimal concern for them. In many instances, this feeling of "being powerful" also results in fluency.

In the home context they establish relationships in which they are comfortable, and take on social roles as fathers and husbands. Here they are least intimidated because they are accepted by spouses as "more than stutterers" and have little difficulty with children who are of no threat to them. They are "able" fathers and husbands who have little difficulty speaking on a daily basis, reinforcing their self-identities as Able/Potential. As they establish careers and families, the self as DisOther begins to occupy a marginal status. They begin to stabilise and foreground themselves as able and with potential. Gareth, in particular, stabilises and foregrounds his self-identity Able/Potential over a period of thirty years. Sagren also begins with the process of stabilising his self-identity, but is in the early stages of this process, compared with Gareth.

As they become established in their careers, they are regarded as knowledgeable and respected professionals, for which they gain social validation thus reinforcing their identity as Able/Potential. They continue to stabilise this self-identity as Able/Potential during their adult lives and by retirement, Gareth records that there are *"very few people who I find intimidate me"*. The stutter also fades into non-existence *"as the forces which held them together are no longer there"*. What are those forces? Gareth explains this as: being able to think that there is more to you than stuttering, of reconstructing what other people might be thinking of you, considering the possibility that they can and do see you in a positive light, and perhaps not even caring what others think.

Although self-identities as DisOther and Able/Potential continue to compete, Gareth and Sagren begin to reconcile these into understanding who they are. They do not struggle against the Self as DisOther but rather "struggle" with it. In this regard there is a sense of acceptance of self-identity as DisOther within an expanding trajectory of Becoming Someone. The "reconciliation" of selves comes partly through a history of living with a stutter but also through the challenging dominant stereotypes of PWS. As active members of a support group, they begin to reframe traditional, public discourses about PWS. Within an activist discourse they acknowledge stuttering as an impairment but challenge the view that they are abnormal or disabled or that they should be defined by it. They contest potential and actual discriminations and prejudices existing within the public domain. Their challenges occur amid wider and changing social circumstances which encourage that the voices of people on the "margins" should be heard. As part of the support group, they each conclude that PWS have the potential to be successful people. They continue to do battle with a social world which portrays negative stereotypes of PWS. In response, they participate in (re)educating the public about their potential and promote an understanding of PWS within a discourse of ability.

In summary, Sagren and Gareth strengthen their self-identity trajectories as Able/Potential in adulthood by personal appropriation and manipulation of social power. They also engage with an activism discourse and contest the problematic stereotypical views of PWS. This occurs in a South African society which promotes ideologies of equity, particularly in the domain of disability politics. As their self-identities become strengthened and dominant in adulthood, stuttering becomes less problematic.

Genesis of Self-Identity as Able/Potential

I have discussed the particulars of each participant in detail to retain the specificities, and to highlight the variability of the critical turning points, phases and the strategies used to strengthen their self-identities as Able/Potential. It is evident that the social and individual forces shape one's self-identity as DisOther, also shapes one's self-identity as Able/Potential. The genesis of self-identity as Able/Potential is summarised below in Figure 4.

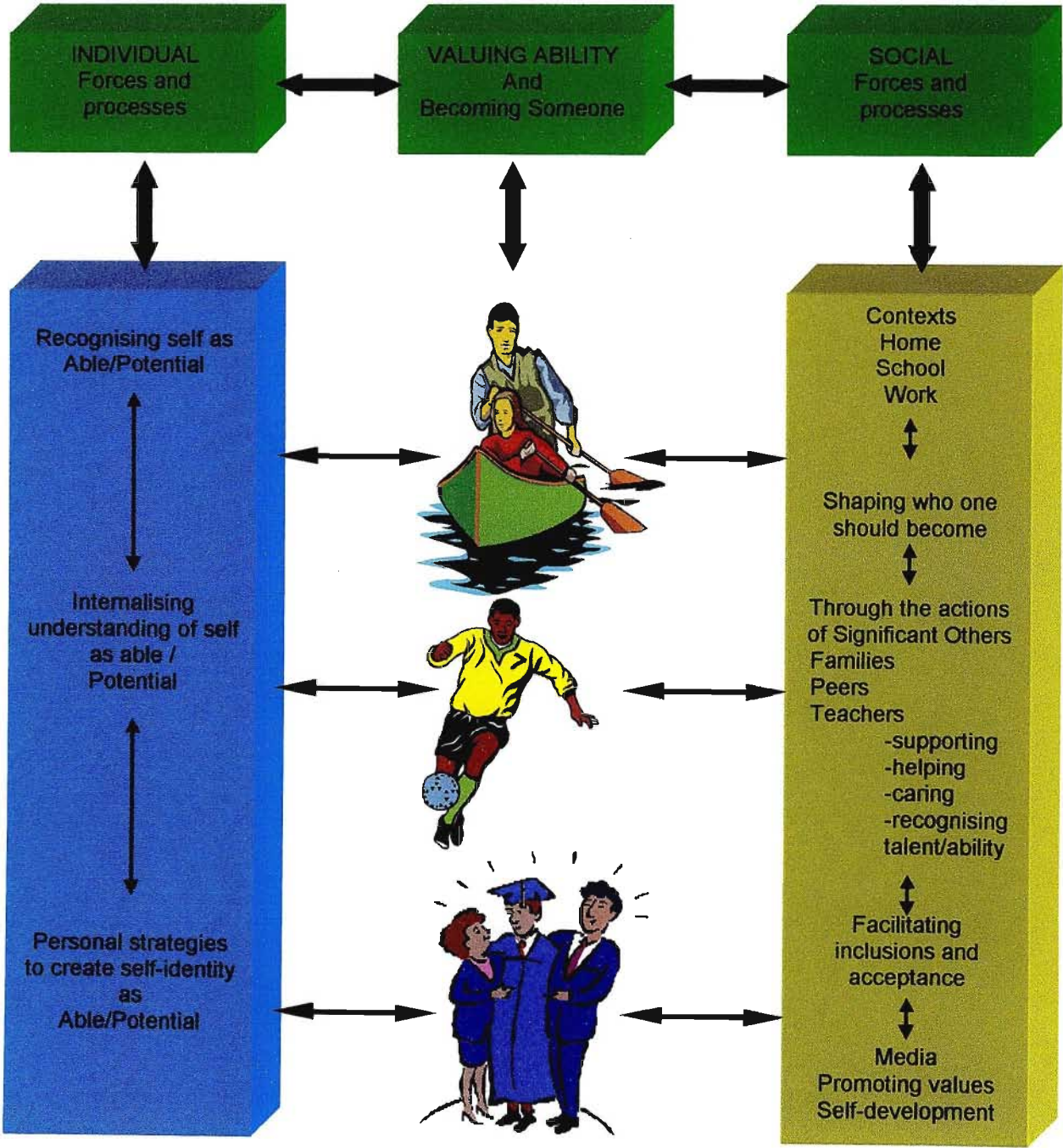


Figure 4: Genesis of Self-Identity as Able/Potential

The self-identity formations are shaped differently in each story. For many, life begins with participants understanding themselves as able or normal. In the early years Significant Others and particularly parents create future identities of their children who stutter. They encourage them to get a good education and to excel in the academic arena, which becomes an important avenue for creating people as successful adults. There are critical points/contexts in each story where participants come to understand themselves as able: on the sports field, and the classroom. Becoming able, in varying ways, allows them to feel more empowered, and for some it becomes a primary strategy by which they negotiate their competing self-identities as DisOther. During school years they are also shaped with intention to Become Someone in society. The importance of becoming professional people with economic access is evident in most stories. In a context of inequality across races participants of Black and Indian communities are encouraged to Become Someone as a means of gaining access to the world of work. Who one should become therefore is largely driven by the value of society and what is promoted within local relational networks.

The personal strategies participants develop to create themselves as Able/Potential are diverse, and are shaped by their relational networks, that is, their communities at school, home and work. Gareth and Sagren develop strategies which are both similar and different to those of Kumari. As a female with a particular history, her strategy relies on spiritual development, more so than for others. Siyanda's strategy varies from others' because of how his life unfolded in a particular political climate. This shows that there are multiple ways in which self-identity as Able/Potential can be created. Each person in the context of his life will come to a particular understanding of what being able is and how to become able.

Through the stories it also becomes apparent that participants generate multiple understandings of who they are rather than only a unitary understanding as one who stutters. Becoming Someone can be understood as a moral thread of their stories. They seek to generate an understanding of themselves as "more than PWS". This occurs in the midst of how society shapes one. It becomes evident that despite the stereotypical notions held by society about PWS, there is also a competing value-system which promotes living successfully (with stuttering). Their actions therefore are multiple and complex, as they seek to promote an understanding of themselves as able. Importantly, these strategies are not limited to changing fluency patterns but are rather about being knowledgeable, socially-skilled and powerful at the communicative interface. This is a dramatic shift from "managing stuttering" to acting

in a way that allows one to be recognised in a positive way. It resonates with Frank's (1997) observation that people living with problems frequently make a shift from asking "How do I deal with this problem?" to "Who do I become?" (to live successfully with stuttering). Whilst this stance is celebratory, it also requires a process of active manoeuvring which develops over time, and is sometimes fashioned through critical moments. Personal agency receives strong illumination as participants tell of their ongoing and persistent attempts at negotiating their self-identities as able. There is no single set of prescriptive strategies that are used but these are constantly negotiated depending on audience, purpose and context.

Becoming Someone is also an "in process" concept because it unfolds through time in context. Although self-identity as Able is actively pursued in adult years, at different points in time participants strive to Become Someone, for example fashioning one's self-identity as a good sportsman during childhood, and then creating an understanding of oneself as a successful professional during adulthood. However, it is also evident that Becoming Someone does not follow neat linear pathways, as in Siyanda's story. His trajectory is disrupted in different ways, when he drops out of school and chose the wrong job. Kumari is a good example of how the process of Becoming Someone appears to be unfolding in a seemingly ordered way, by becoming a graduate, mother but is interpreted differently in the context of her biography. Hence, the importance of the subjective perspective and personal interpretation is paramount in understanding experience.

6.3.2 Foregrounding self-identity as DisOther in adulthood.

During their post-school years, Nontokozo, Thabo and Hennie also expand their biographies and create Able/Potential selves. However, their construction of themselves as DisOther remains foregrounded at the endpoint of each of their stories. Each of them attends university and their experiences unravel differently. Thabo and Nontokozo share similar experiences, unlike Hennie. I highlight the most significant aspects of this experience only.

Nontokozo gains entry into Medical School *because she stutters*. In a rapidly changing South African landscape, access policies at universities were revised after the first democratic elections in 1994, to encourage access of previously "disadvantaged" students to tertiary institutions. The term 'disadvantaged' referred to those who had not been able to access universities because of restrictive policies.

Among those “disadvantaged” were black, female, poor, and disabled people. Nontokozo benefits from policy changes because she is black, female and disabled (stutters). She strategically accepts the label “disabled” to pursue her ambition of being a medical doctor. Her first year at Medical School proves difficult. She feels disempowered because she stutters severely (DisOther), experiences the cultural routines of school, including the curriculum, as alien, and does not have a social support network in a classroom where for the first time she interacts with people of various cultural backgrounds. Nontokozo feels vulnerable especially during the first year.

During this time she is referred for speech therapy with the intention of assisting her to become an “able” doctor. Despite the good intention, this is also a contradiction because she cannot be a “doctor who stutters”. This runs against the cultural image of professional, as one who is powerful and able (fluent). Nontokozo receives marginal benefit from therapy. She is unable to use fluency skills in routine daily communication and continues to stutter. This reinforces her feeling helpless and reinforces self-identity as DisOther. In some contexts, when positioned as a doctor in a typical doctor-patient relationship, her self-identity as Able/Potential is foregrounded. This occurs when she feels she is in a more powerful position. She also suggests that experiences of stuttering, despite being generally negative, contributed to her potential to become a “caring able doctor” (who stutters). She can empathise because she knows what it is like on the “other side”, as one living with a problem. When she is observed and examined, she feels that her self-identity as DisOther is foregrounded, as she is overcome with an extreme sense of vulnerability.

Despite her struggles with speaking, she persists with oral examinations, sustains herself as “able” by being knowledgeable, and passes. She continues to expand her biography positively by passing exams each year, establishing strong personal relationships, and participating in activities she enjoys. Her self-identity as DisOther however, competes aggressively with Self as Able/Potential. However, stuttering continues to remain severe and disruptive contributing to her robust self-identity as DisOther in many contexts. Thabo’s experiences are similar.

Hennie’s experience at university is very different to Thabo and Nontokozo’s. Although he moves away from home to attend university, he does not feel alien since many of his “buddies” attend as a matter of expectation in the white Afrikaner, middle-class community. Furthermore, he creates an understanding of himself as

Able/Potential: he remains friendly, sociable and participates actively in sport, academic and social activities. His self-identity as DisOther remains suppressed and masked because he is able to pass as normal. He "has safety in numbers" where is he "just one of the crowd".

A critical shift occurs as he leaves university and begins to grow concerned about his stutter because he enters the world of work, where the context is vastly different from that of university. Speaking fluently becomes increasingly important as he realises that he is gradually becoming disempowered in social and work contexts. He is unable to control the stutter and pass as normal despite professional therapy. His identity as DisOther becomes prominent and remains a threat to his long-term goal to become a successful businessman and as someone "*superior to the man in the street*". In the future business environment, he anticipates that his stutter will become his greatest threat, and would limit his self-potential in a cultural context which demands perfection and order. He constructs himself as DisOther in relation to powerful, white, executive, knowledgeable men, highlighting the context-specific nature of his self-identity formation.

Hennie is not vulnerable when usually in the company of black men, females or children. It is a specific work context of powerful executive men he must negotiate. Within this environment survival depends on being knowledgeable and those who are knowledgeable are fluent. Stuttering is associated with being "*stupid*" and "*not knowing*". It is also an environment in which stuttering is considered a problem and PWS are perceived as unsure, those who don't know and are unable to convince. The "*packaging and presentation*" is of primary importance in this context and Hennie is extremely threatened because his potential will be masked and jeopardised by his stutter. His self-identity as DisOther is foregrounded and he is desperate for a solution to his predicament. He "re-diagnoses" his problem as one that has to do with poor self-confidence, self-esteem and self-concept. He decides to attend a self-development programme as a means of recreating his identity as Able/Potential, and negotiating stuttering successfully.

In Thabo, Nontokozo and Hennie's stories, self-identity as Able/Potential competes aggressively with self-identity as DisOther/ Other. Their self-identities as DisOther are frequently foregrounded as one gains a sense that stuttering is a significant problem which occupies a central position in their lives, in particular contexts. Despite their difficulties they also expand their biographical possibilities and potential to be

successful, providing a sense of agency rather than passive acceptance despite their difficult circumstances.

In this chapter I traced the formation of self-identity trajectories as DisOther and Able/Potential over time, for all participants. The trajectories unravel in varied ways across participants' experience, suggesting that each experience was uniquely shaped by a combination of biographical, social and contextual forces, over time. The unfolding trajectories vary in their relationship with each other over context and time therefore resulting in a dynamic experience of stuttering. In school years, self-identity formations as DisOther and Able/Potential are shaped by critical events, significant people and biographical circumstances. The school emerges as a specific and common context in which self-identity as DisOther is formed and reinforced. Strategies to manage their stuttering include concealing and passing, and are shaped by the responses of Significant Others. During adulthood, there is a strengthening of self-identity as Able/Potential, which is used as a strategy to manage stuttering successfully in some biographies. The strengthening of self-identity as Able/Potential unfolds in particular ways in their biographies. This suggests that there are multiple and alternative ways of Becoming Someone and negotiating stuttering. In the next chapter I draw the discussion to a close by providing a further set of abstractions emerging from this interpretation.

CHAPTER SEVEN

ABSTRACTIONS AND EXPLANATORY CONSTRUCTS

The purpose of this chapter is to provide a set of abstractions, explanatory concepts and discussion points which respond to the critical questions, and the overarching interest guiding this study: how participants experienced and negotiated stuttering in their lifeworlds over time. I have summarized and represented the abstractions and explanatory concepts in Figure Five which I use as a basis for discussion. These are based on the analysis presented in Chapter 6. I discuss the abstractions and explanatory concepts in relation to the self-identity trajectories, that of Able/Potential and DisOther.

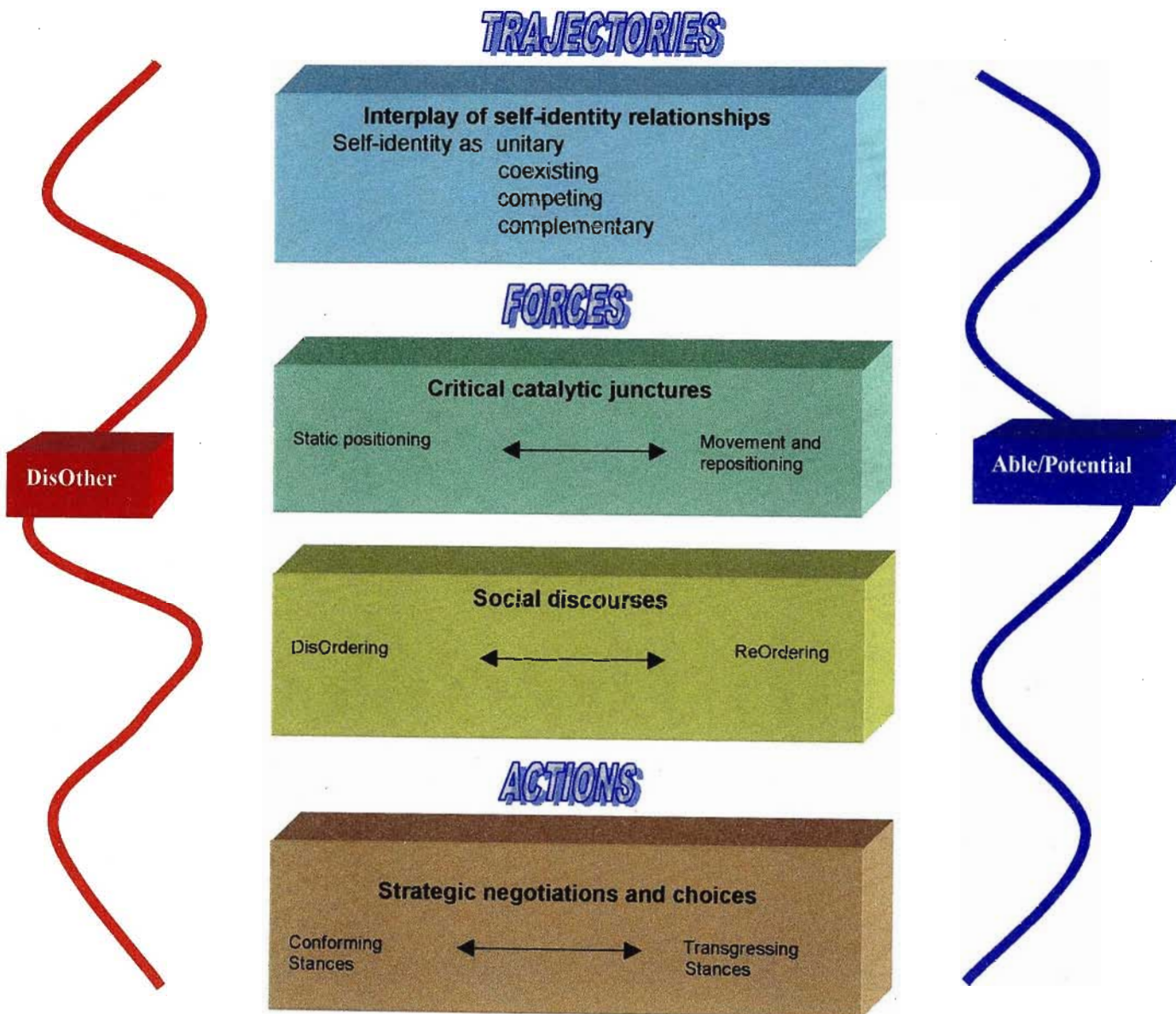


Fig. 5: Summary of abstractions and explanatory concepts

7.1 Relationships between self-identity trajectories over time

In the research stories and the analysis I explored the dynamic nature of experience by presenting how stuttering is experienced and negotiated through the medium of two primary self-identity trajectories over time. Throughout the discussion it also became apparent that the relationship between the self-identities as Able/Potential and DisOther are in different and changing relations to each other. It is the nature of this dialogic relationship which shapes how the experiences of stuttering unfold. There are four relationships between the self-identity trajectories, which become prominent in the research stories. These are represented in the Figure 6.

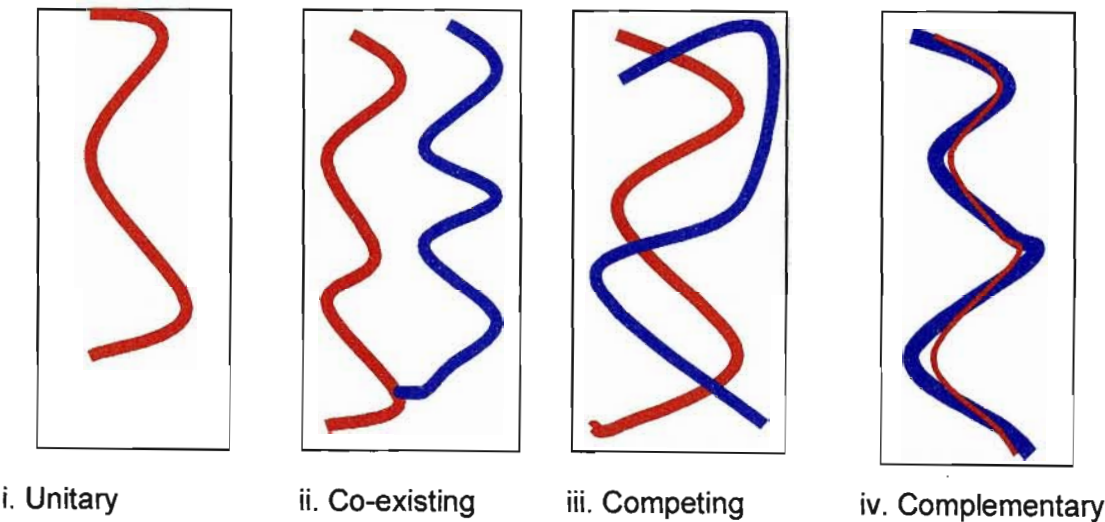


Fig. 6: Multiple relationships between self-identities: Able/Potential and DisOther

i. Unitary self identity

At points in the stories there appear to be a single and dominant self-identity, for instance during the early years, or prior to school or (for some) during school years when participants have a single and primary understanding of themselves as Able/Potential. In this time period, and across contexts, stuttering receives no particular meaning. It is also possible to have a unitary self-identity as DisOther. It is through these self-understandings that their actions become meaningful. For example, if one had a unitary self-understanding as able and stuttering receives no negative meaning, the individual communicates “freely” with no specific attention to stuttering. Similarly, a unitary self-identity as DisOther results in stuttering being experienced as a major problem resulting in a range of actions including silence and concealing.

ii. Co-existing

I describe the relationship as co-existing when both self-identity formations are available in the biography, but may be foregrounded differently across contexts. For example, on the playground one may have a self-identity as Able/Potential, and in the classroom as DisOther. Therefore, the experience of stuttering unfolds differently across contexts as self-understandings change across contexts. The strategies to negotiate stuttering remain dependent therefore on “Who I am?” in a particular context, and are therefore likely to be different across contexts.

iii. Competing

The self-identity trajectories also compete for dominance. Here, both trajectories are available in a given context. Each self-identity is underpinned by a particular set of beliefs and ideologies which compete for dominance within a context. As a consequence of the competing relationship, and dialogue between the self-identities, there appears to be a sense of struggle arising from the interplay of dominances. The contexts and situations are dynamic, and therefore these competing arrangements also fluctuate. The choices made depend on how the dominances unfold. As a consequence there may be a combination of actions, chosen strategically at different points. For example, the actions may include concealing, silence or participation when feeling confident and strategic management of conversations. This competing relationship appears to feature prominently in the biographies, suggesting that multiple understandings prevail, and that actions are constantly negotiated in social contexts.

iv. Complementary

In some biographies there are complementary relationships between the self-identities at particular points in the story. The self-identities appear to “coalesce”, suggesting that there is a “harmonising” relationship between them and an “acceptance” of DisOther. However, the relationship remains political because there appears to be a “dominance” of self as Able/Potential which appears to subsume the DisOther trajectory. These relationships are also personally-tempered and the extent of the harmony between the trajectories and choices made may vary. They range from a sense of being an able PWS (able with a stutter), to one who is able and

accepts the stutter, but continues to retain stuttering within a discourse of pathology (able but stutters).

While I have separated these relationships for the purposes of conceptual clarity, they are in dynamic states within and across contexts and over time, therefore rendering the experience and strategies to negotiate stuttering fluid and in a state of flux. Over time in a single story, varying relational configurations may emerge. For example, a unitary self-identity in early life is followed by a co-existing and competing relationship and possibly a complementary relationship. These may continue to change depending on life realities.

7.2 Critical catalysts, crucial choices and changes over time

The emphasis in this part of the discussion is on temporality and change. At which points, and how are self-identities shaped and changed? Within each story the trajectories of DisOther/Other and Able/Potential are continually shaped over time. Here I consider the turning points, critical events, critical time periods, and Significant People as *critical catalysts* which significantly shape self-identities in a particular way and hence influence how stuttering is experienced. For example, a critical classroom event becomes important in shaping one's self-identity as DisOther, highlighting the influence of Significant Others who shape who one becomes, over time. Similarly, a parent who reinforces and encourages the child who stutters to pursue a professional career, also becomes the catalyst shaping the trajectory as Able/Potential. The point I emphasise is that life events and Significant Others contribute to shaping experiences.

However, the events in themselves are not meaningful unless they receive personal interpretation. Participants make *crucial choices* at these critical catalytic junctures which influence the formation of their trajectories. The choices an individual makes can reinforce a particular identity formation as Able/Potential or DisOther or generate alternative self-identities. It is therefore important to understand how the particular events or influences shape self-identity formations in combination with the crucial choices made.

While self-identities and the relationships between them unfold unevenly within and across biographies, there is also some degree of patterning with regard to self-identity patterns within and across the stories. Firstly, the patterning across these

research stories indicates that the trajectory of DisOther is created and remains prominent in childhood years (up to high school) *in some biographies*. Secondly, in contrast, the dominance of self-identity as Able/Potential becomes foregrounded at different times, but prominent during adulthood. Although movement and repositioning in the direction of creating self-understanding as Able/Potential occurs throughout the research stories, such repositioning appears to occur to a greater extent in adulthood. Why this occurs is subject to speculation. Is self-identity as DisOther more evident earlier on in life because some children are more vulnerable? Is it because stuttering is a childhood phenomenon and as a consequence children are having to negotiate changing self-understandings early in life in the context of discourses which pathologise? Is it that adults become more self-reflexive, having lived with stuttering over a lifetime? These are possibilities, and I do not speculate further. I merely want to emphasise that as the experience unravels over a lifetime, patterns of dominance may emerge and change between and within biographies.

It is important to attend to patterns of self-identity formations within a biography because one might find static positioning, repositioning or an interplay across time which help to understand the unfolding experience. By static positioning I refer mainly to the instances when the self-identity trajectory as DisOther becomes reinforced and sedimented over time. This occurs as a consequence of critical catalysts and crucial choices made, giving the impression of a singular or dominant “static” self-identity construction. It reveals a “sad”, unchanging story of struggle where the person appears to be a “victim” of his circumstances and gives the impression of being “trapped”. There is a sedimenting of self-identity formation as DisOther. In contrast, a biography may be shaped dynamically as change and repositioning become prominent through time. The story is more celebratory, and reveals the participant as “heroic” or agentic. Understanding patterns of change, movement and positioning, the impact of critical catalysts and crucial choices, provides an illumination of temporal aspects of experience. It provides insights into how experience of the past shapes the present and has potential to influence the future. The critical movement and repositioning is useful to observe because it signals a shift in a positive direction and shows that dislodging of self-identity as DisOther is possible. However, the likelihood of re-embedding and sedimenting also exists.

The uneven nature of the unfolding trajectories stands in contrast to the stage development model of stuttering. The commonly available categories of beginning,

intermediate and advanced stutterer (Guitar, 1998) cannot be applied easily to the data and interpretation presented here. For example, the beginning stutterer is generally described as a young child who has little or no awareness of stuttering. In contrast, the biographies based on experience rather than symptom cannot offer such neat classifications. The beginning may be “advanced” because of the personal meaning participants make of stuttering at an early age and develop self-identities as DisOther. This trajectory in turn is shaped multifariously through the life course. Therefore, it may also be useful to trace change over time through the lens of experience, to provide an alternative view of how experiences of stuttering unravel over time. This approach is useful in de-linking symptoms of stuttering and personal meaning of stuttering.

7.3 Social contexts and the shaping of experience

The argument I make here is that the stuttering experience is shaped by events unfolding in the social context at a particular time in history. I have explained the importance of the local contexts, and how Significant Others contribute to shaping self-identity formations through their value systems. However, I turn attention here to the political landscape in South Africa in which their experiences unfold. It is a social landscape which is in transition from apartheid to democracy and during which time there are significant shifts in policies and practices in all sectors. Does this changing social and political landscape have any bearing on their experience of stuttering? It would be naïve to assume that in any society there would be a neat, clean change from old to new ways. In a state of transition, old and new policies, values and ideologies coexist, and it is amid this reality that stuttering experiences are shaped.

As a starting point I consider the issue of the dominant construction of stuttering in the biographies. It becomes clear in these biographies that although there are varying understandings of stuttering, the dominant available discourse is that stuttering is a disorder or a problem. How can this be explained? Bauman's thesis provides a useful interpretation. Human activity is directed in the interests of creating order (Bauman, 2000 in Marotta, 2002). PWS live in this order-seeking world in which chaos and uncertainty is not preferred. When people stutter they challenge and destabilise the interactional order at the communicative interface, creating disruption and chaos, both internal and external. Stuttering therefore has come to be labelled and categorised as a DisOrder, something that is not orderly. Given the propensity to “order” in society, it is not unusual therefore that PWS frequently choose to conceal

or remain silent to resurrect orderliness, even temporarily. A society which values “order” and “normality” contributes to shaping how PWS are constructed and responded to. It is not unusual therefore that those in power (parents, teachers, professionals and PWS), seek treatment, correct and pursue fluency in an attempt to create order.

The interests in ordering can also be linked with social value systems in a particular context. In South Africa, the medical model and apartheid have traditionally relied on fixed and single categories of difference e.g. race or disorder within a deficit orientation. For example, stuttering in a medical model and being black within an apartheid system are deficit classifications – disturbing a particular order, hence DisOrder. However, the scenario gets more complex as the multiplicities such as race, gender and class combine, creating multiple advantages or disadvantages.

However, societies also change over time and in South Africa new ideologies become available. These ideological influences are appropriated in various ways into self-identity constructions, shaping the experiences of stuttering. The transition to democracy in South Africa raised to consciousness a human rights agenda and within this discourse self-identities had potential to be reinterpreted. For example, what did it mean to be a black person, a person with disability (stuttering) or a woman within a new discourse. Although categories remain and we still talk about women and black people, their meanings are fluid and contextual. They receive new interpretations offering potential for an alternative shaping of the self-identity that does not necessarily rely on a single (deficiting) construction. Within this discourse which also celebrates multiplicities and diversity, the individual can be constructed from multiple positions in context, favouring a fuller and more able self-identity construction. It therefore becomes possible to construct oneself as “more than a stutterer”, to have multiple understandings of oneself.

Within a changing discourse, stuttering as a phenomenon still prevails. What can change is how people seek to understand and interpret it. In some biographies it takes on an interpretation of difference which in turn is placed on a *diversity* continuum rather than a *disorder* continuum. Consequently, the response to the “Who am I?” question also changes, suggesting that it is possible to both speak with a stutter, a difference, and still be communicative. That is, there is a ReOrdering or “new ordering”, not a DisOrdering. In contrast to a limited single categorical construction of DisOther, there is an ideological space to construct oneself as both

similar and different to others. Ideologies such as the African Renaissance, democracy, and the changing policies in academic institutions in the biographies are examples that illuminate how new discourses filter into individual lives in these biographies. The support group activities located within a realm of disability activism serve to challenge the dominant public stereotypical constructions of PWS and to reconstruct PWS as able and with potential. They do this by borrowing on broader enabling social discourses. However, the old coexists with the new. It is possible that the impact of renewed constructions are greatest among themselves as PWS. They are not dissimilar to Black Consciousness and Gay and Lesbian movements which still struggle against a world which continues to construct them people as “kaffirs” and “fags”.

In concluding, I surmise that the social contexts in which PWS live shape how they create self-understandings, and hence their experiences of stuttering. They may choose, from the competing discourses, how they want to create themselves and live with stuttering. How much of a choice they have is contestable. While new dialogues and democratic agendas hold promise for changing possibilities, it would be naïve to assume that it will automatically and wholly replace dominant traditions. I wonder therefore whether the self-identity as DisOther will continue to dominate because societies may continue to retain an interpretation of stuttering within a discourse of deficit and deviance.

7.4 Conforming and transgressive stances

The significant value of the biographies of those who live successfully with stuttering is that they provide insights into the personal strategies used in making a critical transition from “What I do about stuttering?” (foregrounding identity as DisOther) to “Who do I become to live successfully with stuttering?” (Able/Potential Self). The creation of a self-identity as Able/Potential becomes the most powerful strategy to negotiate stuttering successfully. In this discussion I consider how and why this transition occurs by summarising the generic strategies participants use to create themselves as Able/Potential, as a means of negotiating stuttering successfully. I reiterate the point that because the self-identity trajectories are in multiple relationships with each other, the choices of conforming and transgressive stances are in a state of flux and unfold differently in each biography over time. In this discussion.

I attend particularly to the transgressive stances through which participants strive to Become Someone because it illuminates issues of agency emerging in the biographies, uncommon in stuttering theory. I present only a brief discussion of the conforming stances which serve to reinforce the self-identity as DisOther. The notion of transgression is significant here because it signals a fundamental shift in self-identity rather than a superficial behavioural shift. The transgressive stances include:

- ◆ Questioning and creating a grander purpose in life and imagining possibilities
- ◆ Advancing enabling ideologies for self-reflexivity
- ◆ Resourcing, strengthening and actioning
- ◆ Challenging, protesting and dialoguing with society
- ◆ Reconciling disparate/competing selves

7.4.1 Grander Purpose in life and imagining possibilities

Participants question and reflect on their purpose in life in different ways. This may not occur only on a singular occasion but also sporadically through life, especially at critical junctures. What is their purpose in life? The purposes vary in the context of each biography and range from becoming successful business men to discovering their divinity to becoming a community educator upon receiving guidance from ancestral spirits: dreams fashioned in local worlds. There are limitless possibilities, and the process is ongoing for individuals as they imagine their futures over time. For some it is the stuttering event which creates the occasion for self-reflexivity, while for others it is embedded within other life concerns. The “problem” or “threat” creates fertile ground for questioning themselves. For others the questioning may begin as a consequence of life events or Significant Others. What is important is that their purposes in life are not restricted to how they manage stuttering but a much grander question about who I want to become.

How does this influence their experience of stuttering? In most instances stuttering becomes less of an issue, or peripheral as they work toward a greater end. This strengthens their self-identities as Able/Potential. However, the strengthening of self-identity as Able/Potential is necessarily coupled with a set of tools or ideologies, “a game plan” to negotiate a grander purpose. In short, they create a new identity goal, to Become Someone, Able/Potential. They are supported by Significant Others and social discourses, and imagine possibilities for themselves which are not limited by

stuttering. The self-identity as Able/Potential is significant because it provides the dream and the potential to create another reality. Without the creation of such a space for possibility, the trajectory as DisOther may remain dominant, creating a reality of hopelessness.

What might the competing trajectory look like? Is it possible that the person who occupies a static, singular dominant position as DisOther may feel hopeless and unable to reflect, trapped? They may feel that their purposes in life are unattainable because of a stutter, which limits self-potential. We gain glimpses of this in the biographies, of feelings of exceptional frustration when grander purposes are being threatened by the Self as DisOther. In these instances, there may be intention to Become Someone, but it seems improbable because the necessary skills/ideologies are not available. Without creating of potentiality, the trajectory as DisOther can receive single and exclusive focus. In the stories it appears that the intervention focus of speech therapy has been on the trajectory as DisOther. As a consequence primary attention has been fixed on how to manage stuttering.

7.4.2 Enabling ideologies for Self-reflexivity

The creation of a grander purpose in life is coupled with a set of dynamic enabling ideologies, unique to each individual. The enabling ideologies can be regarded as the conceptual tools which participants use as a means to ask "Who am I?" and "How do I Become Someone?". This is a transgressive stance. Their enabling ideologies are generated from varying sources and depending on the individual's beliefs, life circumstances, influences of Significant Others and the ideologies promoted within relational settings (society). The themes of sociological imagination, building inside out, and reinventing the self, are possibilities. There are as many possibilities as there are people. These ideologies, at their core, require self-reflexivity, a questioning and reformulating of "Who I am and who do I want to be?" The enabling ideologies are couched in a discourse of asset and potential, of renewal, reinvention and reframing. Importantly, the self-identity is at the core of this reinvention.

In contrast the competing conforming stances may continue to be couched in a deficitting discourse, about what I don't have and can't do having potential to create and sediment the trajectory as DisOther.

7.4.3 Resourcing and Actioning

The enabling ideologies are coupled with an action plan, although not necessarily prescriptive and linear, about realising potential. Participants actively resource themselves via thoughts, actions and emotions in a direction that allows for the self-identity to be strengthened. Resourcing may occur via formal or informal means and does not necessarily serve the specific end of coping or eliminating stuttering. However, because the Self as Able resources and strengthens itself, it has potential to mask and create dominance over Self as DisOther. Therefore, while the stutter may remain it receives little negative meaning. It loses a “defining” allowing for Self as Able/Potential to be fashioned. Self-identity as Able/Potential can be powerful, stable and able to dominate, but has potential to be equally fragile when in a threatening context. Their resourcing includes combinations of cognitive, emotional, communicative and spiritual strategies which coalesce at the social interface. Developing a superior knowledge base, enhanced communicative strategies, skills for self-reflexivity, and a spiritual strength which offers peace and inner strength, accumulate over time. These resources are actioned in strategic and pragmatic ways depending largely on the context. Pragmatic and strategic resourcing and actioning are an integral part of daily activities. The actions are not necessarily directed at changing speech patterns although this may be included as part of a pragmatic strategy of being able in varied contexts.

The Self as DisOther also acts, but these actions do not necessarily serve the ends of strengthening ability in the long-term in a positive way. Their resources are available but limited to negotiating status as DisOther, to passing and concealing, reducing the interactional disorder as a self-protective measure. PWS choose how to act, even if the choice is to remain silent.

7.4.4 Challenging, protesting, dialoguing

As part of a cumulative resource, participants actively challenge the public stereotypes of PWS. They register their protests in different ways and seek to portray an understanding of PWS within a discourse of ability and possibility. They are aware of the social constructions of stuttering and understand their oppression within a broader landscape. Although they understand stuttering as their (individual) problem, they are able to articulate society's role in perpetuating the creation of negative stereotypes. They emphasise the importance of understanding their oppression in

seeking their (possible) freedom, realising that they will continually engage the debate (dialogue) in diverse social contexts. Some actively seek to create new positive public images about PWS through the media or in local contexts. Their challenges and protests are not restricted to stuttering, but also to other discriminations, for example, gender, class and race.

In contrast, the Self as DisOther may be consumed by a dominant social discourse. The individual may “feel” the oppression but not necessarily “theorise” or challenge it, especially in childhood. By internalising the pathologising discourses available in society, they have potential to generate their own oppression by conforming to beliefs of themselves as less-than and disabled.

7.4.5 Reconciling competing self-identities

While self-identities compete for dominance, there are points in some biographies where they become reconciled. For those who live successfully with stuttering and create selves as Able/Potential, there is a realisation at some point that their self-identity as DisOther must be “accepted” and perhaps even liked. There is an attitude of “don’t fight it - invite it”, “befriend the enemy”, “accept the stutter” and “struggle with it and not against it.” They reconcile the stutter as part of who they are, as part of their “heterogenous” self-identity and create the possibility that one could be able with a stutter. As I have already explained, these reconciliations occur differentially across biographies across time.

However, these reconciliations come through conflict and dialogue between the self-identities. Firstly, the dialogue can occur only when there is a creation of competing self-understandings, that is when more than one set of understandings about who one is becomes available. For example, if self-identity as DisOther was the only unitary understanding an individual had about himself, then there would be only a single available, oppressive, self-defining discourse. The dialogue becomes possible when a new and alternative set of beliefs about “Who I am” becomes available. In some ways the two sets of beliefs may be in conflict, but it is through this conflict and dialogue that new meaning becomes possible, a reconciliation through necessary conflict. Although “conflict” frequently has a negative connotation, in this context I use it to suggest that different points of view about who one is can be a healthy thing, because they have potential to develop new self-understandings which can take one to a different and better place: a reconciliation.

In the competing dialogue the Self as DisOther and Self-as-Able remain separate, and resist integration over time. For those who continue as DisOther, there is a need to eliminate the stutter or get rid of the stutter as there is a struggle “against” it. They require that the stutter disappears and self-identity as DisOther be obliterated so that they can be normal and able. They find it difficult to contemplate living successfully with a stutter.

The story of potential, of Becoming Someone, is not only about personal choice. It is shaped by the social landscape. The intention of Becoming Someone and of adopting transgressive stances occurs within society. Is the grander strategy of ReOrdering or becoming a (new) normal, to be like everyone else? Is it another means of being “able” to receive acceptance and value in a society which shuns disability? The changing social discourses about living with disability have shifted from passive acceptance of problems to living successfully with disorder/disability. *Being able is a virtuous state* to which all people, including people with “disabilities” must aspire. Education systems, parents and media promote who one should become and therefore the transitions to Becoming Someone are shaped on a daily basis in local environments. Although not discounting the personal motivations and desires of people to Become Someone, its shaping by society cannot be overlooked. It can be interpreted as a broader strategy to “normalise”, to be accepted as part of society.

7.5 Concluding Comment

I use a metaphor “Multiple dialogues among selves, society and time” as a summarising device for understanding the experience of stuttering in lifeworlds over time. The experience unfolds as a “polyphonic discursive” space between individuals, society and local contexts, changing over time. As a consequence, the experience is fluid and in a state of flux. The self-identities are in ongoing dialogue with each other and are informed by different beliefs, value systems and behaviours. As a consequence of their dialogues and negotiations of power, choices are made about how to negotiate stuttering in context.

The individual, a “heterogenous self” is in turn in conversation with changing and multiple discourses in society, shaping experience dynamically. Enabling ideologies have potential to influence self-constructions as do “disabling” ideologies which foreground deficit as a primary orientation. Within these biographies participants

draw on various and changing social discourses to create their self-identities, and hence manage stuttering. The individual and social dialogues are ongoing.

The dialogue also extends over time. Societies and selves, past, present and future dialogue with each other. Social and individual forces interact variably over time configuring self-identity formations. Therefore, there is no simple way of understanding how stuttering is experienced in a lifeworld. Hence my choice of the metaphor of “multiple dialogues among selves, society and time” which continuously shapes experiences of stuttering and influence how it is negotiated.

CHAPTER EIGHT

REFLECTIONS, LIMITATIONS, IMPLICATIONS

COMING HOME

This chapter is about coming home. I have played, explored and learned in disciplinary fields outside of Speech-Language Pathology with intention to create new knowledge. I have created some theory and new understandings, and now it is time to take them back home, where I belong, to reflect, critique and ponder on its implications. Upon completing the theorising, which proved to be a long, and emotionally-tiring process, I felt I had exhausted my personal resources. I was in need of dialogue to reflect critically on the methodological, theoretical and clinical implications, and consider the limitations of this offering. I therefore invited my colleagues, who were close to the project in different ways, to participate in this process. I chose my conversational partners because they knew the project well enough to interrogate it, and ask difficult questions and consider its contributions and limitations.

The conversation was a difficult thing to do because I was scared of risks involved in putting my work "out there". I recorded two conversations. The first conversation was with myself (H) and Mershen Pillay (M) who knew the very well study. The second was with Sandhya Chetty (S), Penny Flack (P), Mershen Pillay and Farhana Khan (F) who are educators, clinical practitioners and post-graduate students at the University of Durban-Westville, in the Discipline of Speech-Language Pathology and Audiology. I present the three main emphases in our discussion: Research, clinical practice and educational reflections. In relation to these issues I discuss the implications and limitations of this study. I transcribed the conversations and present an edited version of our conversations here.

8.1 Research Process

The battles and limitations

M: What were the difficult parts of this research process?

H: Traditionally, in the interview situation, or when administering a questionnaire, you almost assume that you don't let yourself in as a researcher, that you stand as an objective outsider so you don't "contaminate" the data, although you have because you asked the questions and set the frame. However, this process is intersubjective, and you must let yourself in, but also to know how you are influencing the process. I know I have made a big deal about the researcher-as-instrument, but I think it is critical in a study of this nature. The thing is that I had to let myself in. I had to learn about the value of my emotions as part of the sense-making. I call it an "affective approximation". If you don't feel, you are likely to miss the point. Letting yourself in also calls for introspection about who you are, and even why you feel in the way you do. The researcher has to be reflexive. You cannot understand the other person without questioning who you are. The difficulty was that I read this in the literature, but only really appreciated this during the research process. The problem is that being reflexive it isn't an easy thing to do. There are few practical guidelines about how to become reflexive. My constant concern was always about whether there was sufficient reflexive activity on my part. I was constantly aware that there were limits on my own horizons. What if I missed big and important issues because I just didn't know?

Therefore, during this process I found our conversations and the many conversations with other people through the research process, very important. It strengthens the process. For example, you (Mershen) were able to question my interpretations, values, historical ways of understanding issues forcing me to position and reposition myself so that I could also see things differently. Self-reflexivity is dialogic activity as the study also reveals. Of course, there are always the dialogues with oneself and dialogues as one interacts with texts.

The other aspect which was difficult was that the interview was very open-ended and this was threatening, especially at points where I couldn't follow what was being said because I didn't know. I battled with the conversations I had with Kumari at points because she knew so much about spirituality and I didn't. It was important to interact,

learn and read a lot. The process is mutually-educative as Bakhtin (1984) explains. I learned about other worlds and different worlds. Fortunately, with prolonged engagement there was opportunity for me to grow as a researcher, I could go back to some of the issues I missed during the initial stages. It is not a neat tidy process. I learned and changed all the time. I felt that I didn't know enough at the outset, and that was really unsettling. I also felt that I could have explored some issues in greater depth e.g. issues of sexuality, racism in the context of life experiences but I lacked the experience to engage with topics that I think may be very important, but that I didn't feel comfortable to explore. I feel that I have only begun to understand the deeply political nature of society. It is only through this project that I have dabbled with topics in Sociology, and in many ways I feel like I want to become a scholar in that discipline. It seems compulsory when working with people.

M: I know you struggled with the analysis part of the process. Why?

H: The analysis process is so open-ended and generative. Each time I looked at the data, I saw different things. I also think that my history as a researcher never left me. I seem to carry positivist tendencies with me, and so at one point I reduced the data into little boxes trying to separate out factors rather than show how the reality was configured in a complex way. I also found that I was still inclined to listen to the story of pathology, and that I remained stuck with that for a while because I couldn't make sense of the rest of the story. It was only after reading Frank's work on potential consciousness in stories that the analysis began to make more sense. However, I think that even with the story of pathology, it is important to listen to the suffering because traditionally we have not acknowledged even this aspect. I really struggled to put together this configurative understanding, which is the value of the life history approach. There was so much to cover in a complex life. Even now, I feel that there are issues I haven't attended to sufficiently e.g. psychological impact of early memories, the vast complexity of the self-identity.

The analysis is still reductionistic, and will never be anything close to real life. The one concern I had during the analysis process was that the identity trajectories were multiple and constantly changing, and that in choosing two self-identity trajectories i.e. DisOther and Able/potential that I was reducing the complex data. I did this to develop a semblance of intelligibility. However, while reductionistic, I believe it is still useful. I was also concerned that in clustering these self-identity formations it might appear that I was introducing another binary or dualism. These trajectories are not

intended to be “either/or “ constructions. They are intended to signal multiplicities and varying self-understandings. One could be both able/potential and DisOther.

When I completed the analysis I felt scared to put it “out there” because it is unfamiliar and foreign, even to me. The analysis process is generative and creative. I was discussing issues I had previously had little understanding of. I felt threatened “seeing things from the other side”. Now the Pandora’s box was open and I had to make some sense of it. I had a responsibility for making some sense of these complex experiences. There was also the joy of learning a different discourse. Issues of self, multiplicities of the self, power, gender, social construction were never part of my realm of professional experience. As Noel Gough, an astute educational researcher from Australia advised at a seminar presentation I attended was that the joy in this kind of work is not to generate facts and certainties, but rather to reduce our ignorance with matters we choose to research. I think that is such a sensible approach. Our understandings are always partial and limited. Sometimes in the research process we uncover our blindspots (Wagner, 1993), see things we have never seen before. This was particularly appealing for me. Researching identity formations, and shifting my understanding of stuttering from disorder to person has reduced my ignorance in many ways.

The one issue I did battle with, was the inclusion of social context. I understood that it was important and that there was a need to locate the story within a wider context. It sounds so simple, but context is so vast and complex and it is also difficult to know how to forge the links between the immediate and local worlds and “bigger society”. The theories about the nature of societies are vast. As I began to read the social construction literature, I understood the issues better from medical-sociology and disability activists by reading the works of Brown (1995), Frank (1997, 2001) and Turner (1999). My concern was that life history research was different because it requires a social context for understanding. This perspective had to be retained throughout the interview and analysis processes. During the interview I found that I wanted to include the sociological dimensions so much so that I asked specific questions about race or gender even though Josselson (1995) warns against doing this. However, this was not necessarily part of the participant’s experience and seemed to be an artificial insertion. However, once the story flowed it seemed that these dimensions became available and then it seemed to be more suitable to explore particular dimensions in greater depth.

I was also concerned that while social issues were embedded in stories but the participant was not conscientised to it i.e. he told of his oppression but did not understand it. At what point was it the researcher's responsibility to make this overt to the participant? The social reality is so powerful, that "once you see it you can't unsee it". I could see the influence of social values, the workings of institutions more clearly. They are a critical part of understanding the experience as a researcher. Some participants already had an understanding of these issues. Other did not. I feel that it would be important to share these understandings with participants, even if they choose to disagree.

M: If this process is so personal then can one ever be neutral? And what does that mean for knowledge production?

H: It means knowledge construction is never neutral. Researchers, myself included, shape the process every step of the way. I enjoyed the process because I could declare my stance or bias, and reveal who I was, as a researcher. I could be honest. The process allows the space to declare ones values and acknowledges knowledge construction as a political and contested terrain, never neutral. I have chosen to stand on a particular side to hear a particular story. I chose what was important to theorise. I created theory and it is contestable. There is always the danger that one can make the research say what the researcher wants to say, even when all of the processes of consultation occur. The researcher can be powerful and make the participant see his story in the way that she has framed it. All researchers "frame" and bring particular interpretations. However, when it distorts completely what the participant intended, then there is a serious and potentially-hidden ethical concern. In this way the process is always political and can even be dangerous. Participants and researchers will disagree. However, I think that the different perspectives must be declared in the interests of transparency.

Personal learnings and fascinations

M: What did this process mean for you, did you learn anything at a personal level.

I read "Venus on Wheels", a book by Gelya Frank, who records - over a 20 year period, the life history of a person without arms and legs .She said that when a person is judging another what that individual says reflects more closely his/her position than something about the one being judged. It tells about that individual's

position and values and what he/she thinks of the "Other". One research participant said the very same thing. You always judge from where you are standing, and because of who you are. It is about positionality, about angles of vision. When you stand "with" or close to participants you can appreciate a different story. It is not that things are, it is the way I see it. It's about the politics of positionality. I have found that this learning to be very important in the research process, and even in daily life. When you see a naughty child it is not that the child is naughty. It is that you have constructed it in that way. Renuka Vithal always asked the question: Can you see it another way? That's an important question. I think you must be prepared to shift, change position and see the issue from another perspective when doing life history research.

This kind of research process taught me humility. I know now that I know little and cannot ever be called expert, particularly as a researcher. The issues on research and methodology are so vast and complex, that I feel like I have understood a very small bit. There are many different ways of knowing. I have explored a narrative methodology. There are a proliferation of paradigms and methodologies which I would like to engage with. I acknowledge that narrative research is one kind of methodology, and cannot answer every question I will have. I may want to know about issues of prevalence that may include different methodologies. I am in favour of methodological diversity and I feel that narrative research has earned its rightful place as a legitimate methodology and particularly is useful in our profession.

M: We talked a lot about the sensing and connecting, the feminist influences on methodology. What did you learn from this methodology that was so different?

H: It is about the issue of feelings and facts. A methodology based on an empathetic understanding is one which must make sense of feelings. I have come to appreciate that feelings are facts, that they are not in place of facts. In the interview process participants told me about many experiences. When they did, they told about their feelings when making sense of an event. Example, a classroom incident was bad because it *felt* bad. It was the feeling that made the meaning, that allowed the personal sense to be made. It would mean nothing if there was no feeling. So feelings are facts. Personal facts. When we act it is about how we feel. We are not rational thinking beings only, we are also feeling beings - these cannot be separated - feeling is thinking, There are new interesting bodies of literature Nussbaum (2001) "Upheavals of Thought, the Intelligence of emotions" which have major implications

for how we make sense of lives. I find this fascinating. If one does not connect with the emotional layer of experience, then one has missed the meaning.

About those stories

P: What were participants prepared to tell, and who they are prepared to tell it to. Was there a difference between how people told stories either across age or race or anything like that? Was there a good or bad story?

H: They were all different. They told stories in different ways. It was really difficult to say which was a good story or bad. It really depends on the researcher and participants. There were some participants who were really talented storytellers. Gareth was an excellent storyteller and Siyanda was a dramatist. I battled with the people who stuttered severely, and I felt that the process was very taxing for both of us. There was a struggle to get the story, but the story was there, and most valuable. I found that even a few important words told me what was important. It felt good for us to be able to construct this story that would have possibly not been heard had we not gone through the process. I feel sometimes the danger in thinking that because a participant has a severe stutter, he can't tell a story. We presume disability. I really think it is about whether we want to hear or not.

There is a fundamental issue our profession must consider. How do we engage the stories of people who have communication disorders. I have problematised the application of narrative research in the context of stuttering in this study and it is also occurring in aphasia. We are working now with a student who is engaging the life experiences of a person with a head injury and we are considering how to expand the methodology so that we can engage an understanding of experiences.

Whether a story is good or bad also depends on the researcher's skill. I think one can do a bad story which does not have a good plot. One can craft a story poorly as I did in the initial drafts. In these attempts there was too much extraneous information, the selection of issues did not relate to the critical questions, there was a reliance only on the spoken word rather than the meaning of what was being said. The researcher can produce a bad story. It is also difficult sometimes to judge how good a story is especially in the research context. It is really a point where the art and science come together. I was really fortunate therefore to have Michael's input because of his background in literature. I have rekindled an interest in the joys of reading and writing

and I feel that the links between literature and medicine are so close and important. They have a strong and easy alliance. Interpretation lies at the heart of these practices. A good story must represent the meaning, it must be interpretive. Barrow (2000) tells of the importance of narrative and interpretive practice in aphasia.

P: How significant is the relationship between the therapist/researcher and the teller? Would Gareth have told a different story to a male, for example? How can we build that in, especially if it is deep and painful, and we acknowledge that there are places they don't even want to go to? How does one deal with that?

H: A story is always told to someone and for a particular purpose. The first big thing we had to deal with initially that they positioned me as a clinician, and they wanted to share the story of pathology. We had to break out of our moulds to work-in-hyphen. At times I felt there were "barriers" or "discomfort" in speaking about particular issues. There were things they didn't tell me, and that I was afraid to ask. I couldn't ask Gareth some questions because he was an older man, although I think at points we did get to places we never thought we would get to. It is also a "male" thing to tell a story which may appear less emotional. However, it would be wrong to generalise and stereotype. Some male participants were able to openly communicate their feelings more intensely, on occasion, than female. Kumari and I shared a close story because we had been through similar experiences. Her story could only happen between us, because of who she was and who I was. We had a long-standing relationship prior to the research. I think the nature of the relationship is critical but is never the same with each participant.

I think there are always decisions people make about what they want to tell and what they choose not to. It is a respectful relationship and participants have choices about what they wish to share. Researchers might probe sensitive aspects in the interests of greater understanding. The researcher might want to comment on what was "unsaid". There is a story in the few words and silences. For example, when Siyanda told me about the year when his life went awry and he experiences poverty and a sense of helplessness. He said this in a few words, and didn't want to go into too much detail because it was so painful. I didn't probe further but did understand the few words and his painful silence.

M: Ben Okri quote "We are storytelling beings". Whether we tell or write we all have stories. Can everyone tell stories?

H: I think we live in an age where storytelling is popular, especially in the media. Participants didn't have difficulties telling their stories once they were comfortable. However, it would be naïve to assume that everyone would want to tell their story to a relative stranger. In this way life history research is limiting. I wanted to interview Siyanda's twin but he refused. He was not comfortable sharing personal details with strangers.

One is also concerned when doing life history research about the diversity and "representativeness" of the sample. I was concerned that the participants were mainly university graduates. However, they were different in many other ways. Each life is unique and yet between them there are commonalities. I would like to interview people who haven't accessed formal university educations, or those who never regarded stuttering as a problem throughout their lives. However, in the context of a project one has to stop "sampling" at some point.

A disruptive knowledge that could trouble the angels

M: What kind of knowledge is this? How would you describe it?

H: What does it mean to be able to come to this kind of analysis? It raises the kinds of questions Patti Lather asks about whether this is beautiful knowledge, or disruptive knowledge etc. A beautiful knowledge is like perfect knowledge where everything fits together neatly. A tidy, neat, clean neutral knowledge which we have traditionally familiar with, perhaps a knowledge we are "happy" with. I think that this may be, in part, a disruptive knowledge. It might threaten us as a profession. I think that some people will disagree with what is presented here. It presents a different perspective - telling the story from the "other side", theorising issues from a different perspective. However, I think that disruption or conflicting understandings is a good thing because it creates a tension, a space where we can interrogate and debate the issues in the interests of developing our practices.

M: My concern is that people will only react if they if they really hear what you are saying. I think that people can hear the stories and say Wow! Wonderful stories. If they start thinking critically about what you are saying, then they appreciate this offering as different and challenging. If I think about how aphasia research has appropriated a narrative methodology, but they have bastardised it. They have used

it in a very clinical way to understanding pathology using his story, pictures, collages and all of that.

H: Phenomenology?

M: Very much a clinical phenomenology, but yours is different, but only if people decide to read it in that way. It's a great piece of written work but the real worth is how it gets translated into practice.

H: I think that like with every text, people will read and interpret as they wish. We all read and see different things in it. As researchers, our intention has always been to produce knowledge for "good". Despite all the criticism I have levelled at the profession I really don't believe that we are nasty or that our work is ill-intentioned. We have produced "good" knowledge. We wanted to understand the disorder etc. but the consequences have been problematic due to the influence of medical model and its narrow emphasis. The knowledge we have traditionally created and continue to create has become "evil" knowledge because it has made PWS "them" or "Other", not like Us. It is a knowledge which subordinates, making them (PWS) less powerful and without agency.

Why does such knowledge subordinate? Why has it come to be this way? I know this sounds really harsh but we could understand our roles in society as an institution, a profession, which is part of a social mechanism hankering after order. Like the justice system, which roots out criminals and tried to "rehabilitate" them, we screen and identify those with DisOrder, our "odd-bods", those who stutter, have learning disability, language problems and offer to "rehabilitate". We are part of a larger social enterprise. Our role in society has become one of Ordering - their DisOrder. In this way we have become self-righteous gatekeepers of society's value system of how people should be. The knowledge that we have produced therefore has become an evil knowledge that has worked against those we seek to help. Our traditional knowledge creates subalternity. These are fundamental issues we must revisit, as destabilising as they might be. I hope that the understandings I have come to, in some ways works against subalternity. I read a very interesting paper (Timmermans & Gabe, 2002) about the parallels between medicine and criminology as social control agents.

M: Maybe, this is it is the key thing in intervention. Now, the goal is to disrupt society via social institutions like professions. It's the post-colonial response.

H: A postcolonial response that may "trouble the angels", the speech pathologists. Sometimes, I think it is because we don't "know", not because we don't care.

M: That's what I always say. It is not done with malice. But it is difficult to see what you are doing as bad when you don't see yourself as bad. You almost have to recharacterise yourself, stand apart from yourself and ask "If I saw myself as bad, what would I be doing that is bad? And then explore that. I don't think I am bad but I do things that may be bad and things I don't like.

M: What is different about the theory you have generated compared to what is in the existing literature?

H: There are three main offerings I think this theory can make. Firstly, it makes a shift to understanding the PWS and not the disorder/stuttering. This is a big shift because there is a life attached to the disorder. I have deliberately structured the analysis so that the person remains the centre of the analysis - therefore the lens of identity formations was useful. It is about people, their understandings of themselves and the actions they take. The notions of multiplicities and fluidity of identity formations is also a contribution because it features the experience as dynamic and changing and contextual. The traditional issues of "variability of stuttering" receives a different meaning because the emphasis is on the "variations of identities, lives and contexts". It is not that stuttering vary, experiences vary.

It has become possible to understand the PWS as someone who is not necessarily defined by the stutter, someone who is "more than a stutterer". It forces one to create an understanding beyond the symptom of stuttering. The mere presence of a symptom does not constitute a disability. Disability can only be defined in context. The importance of subjective understandings cannot be ignored.

The theory also presents a challenge to the stage or developmental models of stuttering in two ways. Firstly, it shifts the notion of "development" from the stuttering to the PWS. In the context of this theory we can't speak of how the "stutter" develops. We can talk about how self-identities are forming over time – it is a different plane of understanding. Secondly, the progressive stage model of

development receives challenge here. No two lives unfold in exactly the same way although patterns may emerge between them. Against this background, variability and diversity seem to be more useful theoretical constructs when we talk of changes over time. It may be useful to understand where the critical turning points are and the people, events and choices which influence the unfolding trajectory. It serves to inject “life” into the theory.

The third point I have already mentioned. The theory introduces the social dimensions of the experience which have been neglected in our theorising. This understanding is so crucial and yet has been masked in most studies. When the social frame is introduced the “big” picture looks so different. We have taken everything that is socialised and pretended that it is naturalised – we have begun our understanding in stuttering theory with the assumption stuttering is a disorder. It is a social understanding. It is an understanding we have created. I have repeated this point because it is of critical importance to us as a profession. What would happen if some authority decided tomorrow that the classification of stuttering was all wrong. What if we called it a ReOrder rather than a DisOrder. A difference and not a pathology? What would it mean for us to say it is a difference. What would happen in our texts, teaching and clinical interventions. This is the challenge this theory is also making. The lifeworld is making different understandings about stuttering. How do we interact with those?

Not for everyone

M: That’s a lot of new. Do you think narrative research methods are for everyone, for all researchers?

H: It’s foolish to think that everyone would want to do research this way. If you wanted to know something different, like how many children stutter in schools then one must choose different research methods. But if we choose to understand the experiences of people we work then, this methodology is useful. There are always “like-minds”, those researchers who prefer particular methodologies. I believe that methodological diversity is a good thing, and that we can know in different ways. I have explored one such option. I would like to research in different ways.

8.2 Clinical Practice Implications

There is an important issue I must clarify at the outset, i.e. Life history narrative as a research methodology versus life history as a clinical tool. I want to separate these because I think they are different, but interrelated and I want to resist a conflation of the two issues in the context of this discussion. In the study I used life history as a research methodology, as a way of knowing, and generated a set of theoretical outcomes which have practice implications. The potential to use life history narratives as a clinical tool as opposed to the traditional methodologies is also possible. However, I believe that we can appropriate the theory (e.g. multiple identity formations) generated via research into a variety of interventions, even if we don't use a narrative orientation to therapy. e.g. when we talk with parents, or work with PWS, or participate in media campaigns. Narrative Therapy approaches are growing in popularity in many fields e.g. Occupational Therapy uses the concept of therapeutic employment (Mattingly, 1994), including stuttering (Manning, 2002).

Die gelukkige hakelaars? (The happy stutterers) What promises can we make to PWS?

P: I remember years and years ago, just after I qualified I went to an in-service training and there was this Afrikaans therapist in the education department and she said basically what can we do about stuttering? We can just make them Gelukkige Hakelaars. It stayed with me forever, because we can't promise fluency, we can't promise cure and all those debates. So, its always been a case of well we should make you a "happy" stutterer, happy with the way you sound, and that is what came through so clearly in the stories. Those who moved on, and you speak of them realising their potential, like people like Gareth, they were happy with who they were. That is something which would shape or reshape the whole focus of what we do. It was not really about fluency issues and techniques. It meant hardly anything to any of them. It has to do with issues of identity and self-esteem, with how stuttering is handled very early on in childhood, in their different home contexts and school. It appears that there are some who are going to be okay, and some who are not, whether we intervene or not. That is the cold hard truth. I think that the potential of this offering is so exciting, I mean really, you want to jump up and say where's the first person I can try this with. Have you used any of this in a clinical context?

H: I did a bit of follow through with one of the participants who felt he was in need of help after the story review process. There was no one else he could practically get to and so I offered to help I explained that I would like to use the understandings I generated from the research process because I felt I couldn't just go back to "old" ways in which I had worked. What was so different about that intervention? One of the things was that we didn't only go into measuring the blocks and disfluencies but used his story as a basis for questioning identity as DisOther and those critical events which shaped identity early on. How did this come to be a problem? Why is stuttering a problem in your life? Why was that classroom event so significant that you never spoke for two years thereafter. These events shaped who he was. We also talked a lot about social construction issues, example, what happens when society decides that something is a problem, how stuttering is socially-constructed and belief is that he is "bad" and what it means to live as life time as DisOther. Although he had told me about the social dimensions during the research process, he had not fully understood how society played a role in constructing disorder. We drew parallels between race and society, as Siyanda does in his story. We talked about how being Black was pathologised in apartheid times. As we spoke " it seemed to me like the "lights went on". He began to understand stuttering differently. I feel it is important to understand how social oppressions are generated in one's own life.

The other thing we did which was part of the therapy was the discussion about Selves as Able/ potential and DisOther. We talked about his dominant self-construction in his story, and he was able to understand that his story was a story of DisOther, of a self, feeling trapped. It is very much the story of pathology that we hear at the clinic and is the dominant story and identity promoted in how we work when we construct people as patients. But we also talked about the other parts of his story in which constructs himself as able and with potential e.g. I went to university, did well etc. We talked about the issues of Becoming Someone and the choices he could make acknowledging that society/external pressures which can makes those choices difficult. We explored the possible steps and routes he could consider in creating a self with potential. We also did a bit of fluency work but it was with an understanding of where fluency fits into a "bigger" and the advantages and risks involved. He knew its potential and limits within a broader framework of issues of normalisation. Importantly, understanding the Self as multiple creates potential for dialogue and through it, a reality that one can Become Someone. It is a talk about hope and possibility. I felt more comfortable with what I was doing. It seemed to have more application to the person, and who he was in society.

However, there are also those clients who come in expecting a “medical” understanding and expect a short-term solution and “cure”. I think that it would be a challenge to introduce a narrative methodology when an individual does not understand the “story” as therapeutic. However, the issues generated from the theory could still be introduced.

Life history approach as a therapeutic tool?

P: I really like the idea of narrative as intervention, getting them to talk through, talk it out, getting to that point, facilitating them getting to that point but not offering therapy in the traditional sense. The therapy of “talking it out” was the thing I thought was quite exciting about this offering. What if we say this is now stuttering therapy, we are going to take you back, let’s talk through and help the facilitate the process of seeing of identifying this is what I feel about this and why, to the point where they might even say, “stuff the world, this is me” and that whole DisOtherness goes or is understood.

However, there are some elements of the stories which seemed so complex and difficult to make sense of. For example, how does one make sense of Kumari’s story? She was a wife and a mother and still it didn’t make her who she wanted to be. So how does one recognise that potential? As a therapist you are helping the person to recognise their potential but they don’t even know what that is, what happens when they get to where they want to be, and there still isn’t this sense of wholeness.

H: I think that the Becoming Someone is always in process, you never quite “get there”. You may reach a point where you reach an identity goal and then you decide you want to be Someone else, that’s fine, it’s a journey. I think that Kumari’s story is a classic example of what society expects, who you must become. As a female you must become a wife, a mother or whatever. For her it was bigger than all of that. It was about spirituality and reconnecting with a spiritual sense of self damaged early on Becoming Someone for her was complex.

P: That’s so interesting...

H: Everyone has a different idea of what Becoming Someone is. It may be anything from I want to be the Boss to I want to be a spiritual being, or all of that within a

single being. I feel that we should respect that, and whichever way they choose to live. There is no set standard, and the possibilities for changing who you want to be also exists.

P: What's interesting is I wondered whether she would have reached there on her own or whether it was through the story, and maybe that is the main role of the intervention. I feel that the story may have been the trigger to take her somewhere else, even if it were unintended. Maybe stories do that. Maybe that is how we should see our roles as therapist, to develop the story as triggers.

H: Although my intention was not to use the story in a therapeutic way, it did serve a therapeutic purpose for some participants. Many people are exploring narrative ways of working. I feel it has great potential.

P: What was also interesting for me then was that stuttering often became such a marginal issues and how it got left behind - that process can be so useful, clinically.

H: I think that as the "centres and margins" of ones' life changes. When stuttering is "on the margin" it has less of a defining role in one's self-identity. It isn't foregrounded always as we commonly assume it would. Can you imagine what it would mean for a speech therapist to talk about developing a grander purpose in life, considering a diverse range of strategies for resourcing (which might include fluency), considering how power can be manipulated in favour of the PWS, self-development, life strategies. It creates a different orientation to therapy. It may even challenge whether speech pathologists with their current knowledge bases are able to engage with such interventions and that psychologists are more suited to managing stuttering.

P: How will you evaluate or be held accountable when you use stories in therapy. If you look across your stories, can you say that one had a better deal than the other. How do I say that that person benefited? How would I evaluate?

H: I think it is a difficult thing and I can't answer that now. I don't know really how you would evaluate in a clinical context. Perhaps consider if they understand their own oppressions, evaluate whether they are forming different identities? Consider if they have a competing trajectory which creates the potential for change. Consider whether they are on a trajectory to becoming Someone and are acting consistently to achieve that identity goal. It is a very fluid process and raises many questions to

which there are no simple answers. The issues of relapse and treatment outcomes receive new meanings in the context of issues raised in this study. One could reconfigure relapse in the context of varying relationships between self-identity trajectories.

M: If we don't theorise or understand the other side, with potential, I am worried that if we don't celebrate it, it may become lost within a still dominant medical model.

Problematizing Help

M: The battle I have is can you even claim to say you give help to someone.

P: like how you define help?

M: Yes. The thing that bugs me is that I don't know whether we will ever actually get away from still treating it as a problem. You are still saying that you are the speech therapist and they are still the patient. You will still say to them don't worry you have a problem but it is okay - like transactional analysis –I'm okay, you're okay and all of that. It still smacks of that, and for me is where the problems happens. It may be a different therapy, a new age therapy tool. But it's still therapy.

H: I agree. It's a difficult one because we are still a "helping profession". It would be nice to dismantle social systems and reconfigure "professions" but for now the cold reality is that we make a living from working with people with disorders. Within this reality how do we work the best way we can. I think that there is potential to reposition the patient and the therapist. In the long-term we can work towards something else, something better - whatever that might be. We will always work between our past and future....

M: Labouring affinities – we always work from our history to our future. The present is difficult to negotiate.

H: Exactly that, and it is going to be difficult but I think that we can move somewhere else (better), or stay where we are. In my mind if we stay where we are we are in serious danger of doing damage. As a profession we are part of a system which can do damage. I don't think this kind of theory is a solution but it is a suggestion, asking "Can we move to a different place?" However, even that move is dangerous and

risky. One of the grave dangers is that we can use stories in a way which might create further subordination. There is a danger when I can claim to know your life better than you. I think that we must be willing to at least get to a point where we can negotiate power imbalances in the clinical process to admit intersubjectivity. It is here that I think we should appreciate that we can never stand in the shoes of another. Therefore, we can never own their stories and must work collaboratively for understanding. I think each of us, client and clinician, has a different but valuable knowledge base which we bring into the therapeutic interaction.

Extending our roles: Activism

H: However, I think that you have raised an issue about therapists working outside of the one-to-one therapeutic interaction?

M: Yes, and that's why the story is incidental. In the stories we gain insights into how the social becomes the personal. Where or how in the process do you get someone to engage *directly with the social*. What can you do outside of sitting down together that also looks at them becoming their own advocates.

H: Can they become activists? It's possible. What about you as therapist? Can you become an activist/advocate? I think we may facilitate a process where PWS can become activists. I agree with you, there is need to reconcile what does or should the therapist do to become active outside of the one-on-one therapy. From where I am now, I honestly cannot see myself working only within a traditional therapy model. We can't. I think it would be unethical. We must be out there in the public. The clinical enterprise must consider the social and individual aspects of intervention. The activism dimensions have been neglected in our profession.

F: I haven't been involved very closely with this process but if I hear what Harsha is saying then it has a close parallel to that of Deaf Culture. Deaf people are standing up and depathologising deafness, and they have also become quite a militant force. Like the activism we see with Disability activists, it is the same thing?

H: Yes, the parallels are there. However, as a profession we are the ones who pathologise and so we are caught up in a very difficult situation now. Now the emphasis is on depathologising. Perhaps we must redefine what we do?

M: I just remembered now. I did some work in Lewisham, in London and with a disabled people's organisation and it was very nice. It was people with Down's syndrome, Cerebral Palsy and people who were intellectually okay but people who used to organise themselves. We were part of their team, a social worker, myself and a few others. They were militant, not angry militant, but just active active active. Everything from campaigns to taking over the nightclub on a Sunday night. Now that is the kind of work I would practically like to do.

H: I agree, it is a much bigger work. It is not just the change on the therapeutic front. It is about society and for me these issues have become clearer and more meaningful through this research process. I have been amazed how everything that is social has become natural in every sphere. The pervasive and yet silent values by which societies have been shaped must be problematised and challenged. What struck me most was how the individual can be "colonised" by society. It is through the powerful influence of social discourses that PWS manufacture themselves as different and less-than, creating a heart of darkness.

P: The one thing that stood out for me was that every single one of them had a traumatic, life-shaping event in school. The thing is that the teachers and the other kids in the class probably moved on and never gave it a second thought. To the PWS it was something they would never forget so there as well there is a huge role for educating, for those who try to exclude them by saying "don't worry you don't have to speak" because it still makes them DisOther. I don't think it is a case of doing ourselves out of a job, but the nature of our job has to be different.

H: if you asked me now what would I like to do, I would say I'd like to go to schools. It would be my first point of intervention. Many approaches to therapy include dealing with issues of teasing and activism and I think that the outcomes of this study confirms that these are very important aspects. However, it does raise questions about what we say or the advice we offer. Not everything works for everyone. I was talking about this to Siyanda and he suggested putting together a script which he would like to dramatise at schools, from the issues which emerged in the stories. He is currently working on this.

M: That's like the aphasics theatre I went to in Montreal. A speech therapist started that as her way of being an activist. It is really amazing. They fluff their lines and everything, but there is a bigger message. I like the thing about the school. If you

target different levels within a school, work with the whole school, the kids re-educating, where people monitor what they do with kids, Also, the employment area is a good place to intervene. How would an employer be prejudiced? Why that is so good for us now in South Africa, is that we are in a perfect context. We have Labour Act which says you can't discriminate. Activism can play out beautifully in this context. If you know that something feels wrong you should fight, but I think that it is a personal bias. If you don't want to become an activist then that is okay too. As a profession I think that the activism is missing and that's why I am pushing for it, to move it.

H: Even for those who stutter, activism is an option and choice. There are those who just want to get on with their lives. Are you going to fight or become active every day because you are Black or stutter or as a women. I think you might or you could decide to become active at strategic points e.g. like at job interviews. It is a political strategy. I think it is important that we help to create understandings of people and disabilities within a human rights framework. They can still choose how to act in an informed way, informed by what they understand and feel - even if that action means doing nothing.

S: I think that if you become defined by this one thing of being Black or stutter it might limit who you are. Sometimes you want to be a dreamer and sit on the beach and you don't want to constantly fight.

M: Except to be active you may not fight, if you take on a Gandhian-type philosophy you can resist in different ways. There are so many different ways to act.

P: I think that pushing activism too far can further highlight DisOthering. If I run around being an activist about stuttering, I still make it a central issue in my life. What we are trying to do is make that not the central issue, so there is that sort of dilemma.

M: But we live in a political climate where you must develop a collective identity as a woman or Black – you have to be Other first - to fight - to become regular.

S: It is like what Patti Lather describes, the "Lather flip" (Sandhya's term). First you must move from being at the bottom (oppression) to get to the top (dominate, claim your rights) to make your issue known as a women or Black person, or PWS, and then to engage as equals

P: It's like the medical student in the story who gets accepted because of her disability. Hell, I would rather be accepted because I knew I was going to be a good doctor. And then to make you fluent because you need to be a fluent doctor...

M: Yes, make you something else because you are not good enough as you are...like our students - we want them to come in as Black but leave as White. Like the women in our profession come in as women and leave as men.

P: Rich white men, the norm, the ideal.

S: and to become able and normal, that's our job

F: How much of what has emerged in the theorising can be used in a preventative, educative way. Can we prevent those life-shaping incidents from happening?

H: I don't know. It is possible that we can share this understanding with teachers, parents, society. I don't know whether we can prevent such incidents but it is certainly important to address. May be when such incidents surface in clinical stories we are also mindful of their potential impact and we can help children and significant others to deal with these issues.

M: I still think that the most effective way of sharing these understanding are through the regular channels like the media, books, movies, the regular cultural things. I think that these stories can be useful for parents to read to understand their roles and see the potential their children have as PWS.

H: PWS receive the most negative coverage in the media. Stuttering is constantly linked with being stupid and not knowing...

M: Like in A Fish called Wanda

H: Yes, and those stereotypes need to be challenged. In South Africa, we have had the likes of "Dada Man", a Superhero and PWS, a television interviewer in South Africa. He stutters and interviews and is celebrated, suggesting that it is possible to bring those seemingly disparate ideas together, PWS as "hero".

P: The issues of stereotyping came across in all the stories. They didn't want to stutter and be perceived as stupid. That connection needs to be broken and that is where the activism must be directed.

F: It was like the neurology professor who used to stutter. He used to say to the students "this is how I speak and you either deal with it or you don't." and he would continue with the ward round. A personal activism.

S: If we go back to kids, it is clear that teasing is everywhere. You get teased about being short, tall, fat, kind of hair. It can be a nasty little world, not so innocent.

Not for every clinician or client

F: In the stories it becomes apparent that the stuttering is "side-lined" as the person is dealing with other issues. Fluency disruptions becoming the occasion to think about who you are, for example Christopher Reeve (Superman) who starts to think about his life differently. My concern is whether we as therapists, who are not completely okay with who we are, who haven't necessarily had the opportunity to think about ourselves, can deal effectively with clients. It is a huge responsibility. Have we gotten to the point where we understand ourselves to be able to help clients using this kind of methodology? If I think about me, and my life, then who am I to facilitate this kind of process? Not everyone can do this.

H: There are two issues here. One, I don't think there is anyone in life who doesn't have issues, and I think that if you have issues you may be better placed to help. Secondly, you must reflect and be in-process of knowing yourself. For me the hardest part of the process was to do my own journey. It is difficult to understand the Other life without going back to your own. We have not even touched on who the therapist is, and how she has been socialised, in so far as our own practice goes. Thusfar, we have been powerful but very "anonymous" professionals. I don't think it is impossible for clinician's to work intersubjectively but neither do I think that everyone would want to or needs to work in a similar way. The same debates apply in other disciplines who are using narrative therapeutic methodologies (Lanner, 1999).

P: I think the other critical issue is that how well-equipped you are to deal with difficult issues when you are just newly qualified, compared to when you are twenty

years down the road. We need to reshape our training - may be to have the whole of the first year to allow the students to discover who they are. Maybe that's what we need to do so they come out with an understanding of why it is important to know that and then the importance of generating understanding with clients.

F: But do clinicians need to address the issues in themselves first?

M: I don't think you must address it to yourself - that's the liberal notion, actually you shouldn't have to. You know you have your hassles, so long as you know it, you can help. It is okay if you don't deal with it...

H: That's fine too, it's a choice you have and I think that is important that PWS also have the choice to be who they want be, even if they choose to remain where they are...I have been very concerned about the advice we give to PWS. I think it is really unfair to be prescriptive. I think we could talk about possibilities and options and they should make the choices - even if at a point they choose to be silent. Everyone in their daily lives avoid things, and don't fight every issue all the time. Why should PWS be any different? Sometimes it's almost expected of them to be superhuman. Maybe it is okay to avoid a situation on the odd occasion when you feel greatly threatened.

M: They should not be forced to disclose that they are stutterers if they choose not to. He could end up being a nervous wreck if he can't deal with it. The intervention shouldn't be so goal-orientated.

H: I agree. We often suggest disclosure is a useful strategy but we need to question for whom, when and how. Many participants only opted for disclosure as a strategy when they were comfortable of who they were, with a stutter. They suggest that to have disclosed at an earlier point in their lives would have been devastating. It is really a case of different strokes for different folks. Prescriptions don't work.

That is the best part... the not knowing

M: For me the best part of this kind of methodology is the "not knowing". Is it a women thing?

P: Maybe you are right, maybe women are more comfortable “not knowing” or knowing differently or multiple truths.

M: Maybe a point to start at is that you know a little bit about the disorder. When I meet the PWS I know something about that person, something about stuttering, that is still part of that person’s life. I will acknowledge that 100 % of their lives I don’t know. Stuttering can become the conduit for talking about life issues, a way into their lives. I will go through what I know to who they are. I will feel uncomfortable with a total not knowing...

P: But do you even have to know even that? If we take it to the extremes, in an ideal world. I know about stuttering, I know about fluency, I know that you were likely to have everyone tease you when you are a kid. Then you come across someone who is totally unbothered by it. There is a danger, of knowing or thinking you know. It can be very dangerous...

M: But what I am saying is that I need something, like stuttering as a starting point. It’s like when you meet somebody, like a child and you say “what a sweet little cute thing” it could be a terror, a Damian from the Omen. In anything you always go in knowing something. Then, it could turn you over, and destabilise you and that’s good, it would be useful. I think that naturally we would go in knowing things about each other. We never meet each other naked.

H: I think the problem is when you value only what you know, and close off the possibility of knowing more or different...

M: ...and you push it, your narrow view.

P: It is like what is happening in learning disability research, where we are only looking at failure because that is what we *know* kids have. It is very scary because it is very dangerous depending on the power we give that knowledge. It doesn’t leave much space for developing that other knowledge. We know a lot about the disorder but little about the person with the disorder.

H: It’s similar to what Oliver Sacks says. His very famous quote which I have used goes something like “ask not what disease the person has but what person the

disease has. Sacks argues that no two people will ever have the same experience of a disorder because their lives are different.

F: Yes, exactly what we are trying to understand.

H: We, as professionals /researchers privilege certain types of knowledge of the disorder while PWS bring another set of lifeworld knowledge. We have different "contours" of knowledge. The danger is that lifeworld knowledge is discarded as unimportant. I don't think that knowledge about the disorder is not useful, but these knowledges should be in dialogue.

Not a successor regime

M: Farhana's earlier point is important. Not everybody for every tool. Some people will be comfortable with researching little bits in the lab but there will be a kind of you (Harsha) who will do stories. There will also be the PWS who will not want to engage with stories. All they will want is give me that pill and that will be fine, show me how to slow down my speech. I think that it runs the risk of becoming the new-age deal, or being a "successor".

H: No, it is not a successor or replacement or displacement methodology. It is another voice in the research/clinical dialogue, another way of knowing and doing. I think it is an important but part of a larger clinical enterprise for those who may find it useful. I don't think that stories are necessarily the best tools for everyone either for research or clinical practice. But I do think that the issues emerging, like power, cultural heritages are important, in to whatever kind of methodology you adopt in clinical practice because we are dealing with people. There are those who might never value subjectivity and therefore will not value this research. That's okay.

F: We have only looked at the disorder, and no value has been placed on the person. That is a real problem.

H: It is what Frank (2000a) describes as the difference between the story and the ride. The ride refers to the technical aspects of practice which are important but could become problematic when it is the only thing we do.

S: The thing is if you understand all of this, it is such a freeing thing for the therapist, especially if you are dissatisfied. It is important to learn this kind of methodology as an option, and for the client who may also need it. It is such a thing to know. For me personally, I have avoided fluency therapy because it is boring, it is about blocks and stutters but language therapy is interesting because it gives me a creative edge. But now I feel you can use stories and engage with the person, issues of identity and do the real stuff.

Are we fossilising our irrelevance?

H: The one thing that did come through the stories was the extent to which in the participants in different ways found self-development methodologies useful, and have gone a different route to speech therapy e.g. Oprah, Dr. Phil McGraw, Dale Carnegie. Self-help courses seem to be very useful for them and present a challenge to what we do as a profession.

F: Dr. Phil McGraw uses a life history approach when he asks people to go back to the significant people and defining moments in their lives to understand who they have become and how they can get to another place.

P: and as you have just said in all those other interventions are not looking just for fluency, but looking for self-fulfilment and those are the things threatening us as professionals...

S: it's about self-development. When we try to defend the things we do within speech therapy and our "standards", we are just committing suicide. We are just fossilising the irrelevance. That's it, we are just fossilising. Sometimes when you try new things or take up new challenges, you can sense the block, even with your colleagues, and it is very frustrating.

H: The self-development movement is also cultural. It may be the methodology for the time, but who knows what will happen in ten years. I feel that we can become obsolete if we stay where we are.

P: I don't think obsolete if we change what or where our emphasis should be...

H: On the other hand we still have the power of the medical fraternity behind us, and we will still be expert. What bothers me, even with the self-development culture, is that it also has a tendency to make people good for society. It also places the responsibility for change on the individual and can mask society's role in creating problems.

8.3 Educational implications

S: I think that if we were to use this kind of methodology, we would require a different type of training and level of maturity. I wonder if we should have a specialist type of training?

H: Maybe, the issue of specialist training with Fluency Disorders has been on the international agenda. However, it leaves a huge dilemma about "in the mean time what do I do in the classroom". I don't feel I can teach the traditional without disrupting it. I think that students shouldn't just be comfortable with doing what is traditional and following recipes only. I think that we must keep what we do under constant questioning, both old and new.

F: But our profession has not taken these issues seriously. We tamper with them only. Closer to home, our more immediate problems will be about whether training institutions will accept an idea like this. How are we going to train students differently? What you are suggesting with this thesis will totally blow their minds. Think about the student in lectures. They are going to modules in Aural rehabilitation, Central auditory processing disorders, Language disorders, Phonological disorders and then they come to Fluency disorders. It is different. With every thing else, you are boxing and labelling and say this is how we treat, this is what we assess, use this assessment tool and whatever. And this is different. We have a huge problem because we are accountable to our clients, and there is a lot of undoing that has to happen. I don't know. It is exciting and challenging but I would love to see the response of the so-called academics and institutions because it is really going to blow their minds.

P: I have exactly the same the problem as a clinical educator with learning disability. We all know our therapy is wrong, but we are doing it anyway because it is too big to deal with it, is too messy and too scary. So, we do it saying we know it is wrong and that's the scary thing. We just keep going. I don't think that this theory applies only to

stuttering. I think it is this kind of knowledge is going to shake the foundations of everything, but over years. But in the mean time what's going to happen? We will keep doing what in our minds we know is wrong, because it is comfortable, it's safe, it's quicker - all those things

H: Through the many years of debate about professional development, we have considered research, education and clinical practice to be sites at which we have potential to change. They are all leverage points. I have offered commentary in this project about the need for change in the clinical practice and research contexts. I think how we educate is equally important. I think that there is no point in applying critical perspectives in clinical practice and research without carrying them into classrooms.

As professional educators we always make selections about what to teach. There are always multiple knowledges vying for legitimacy. I will present the range of options and theories. I will also present my ideas and understanding, without intention to be prescriptive but to encourage engagement. Students will make their own choices.

We need to make a shift from technicist orientation to education to a critical one. However the question often is Where does one begin? How much of a "systemic" change is necessary to encourage new ways of learning and thinking to disrupt our traditions? We, at the Department of Speech and Hearing Therapy, UDW have been engaged with processes of curriculum development since 1994. We have interrogated the curriculum content, the teaching-learning assessment methodologies, issues of diversity, service delivery models. However, at a fundamental level we are still framed within a medical model, and it is critical that we reconsider the dialogue between the medical and social aspects of disability in the curriculum. It is no easy task. The issues are complex issues and we lack a theoretical base. If we changed our orientations, what "theory" would we teach? I feel that I have generated some new theory, but it is only a small beginning. Can we wait until we create new theory? I don't think so. In the mean-time we can do something different? I think we can educate students to be intellectuals rather than technicians, but I believe that the re-educating begins with oneself. If one enjoys the "safety" and certainty in "prescriptive" education then the educator may not want be a need to change. At the very core we really need to ask: Education - In whose interest and for what purpose?

I have found it useful to discuss with students the multiple ways in which knowledge can be produced, so that they can critique knowledge, and consider its usefulness. I think it is also important to allow students to construct themselves as knowledge producers so they have the understanding that they too, can produce knowledge, and have important contributions to make. Knowledge production should not be seen as a domain for the few elite.

I have used narratives in the classroom as a teaching tool. The use of stories and narrative approaches in teaching is not new (Greenhalgh & Hurwitz, 1999). The problem is that despite the valuable learning which occurs through stories, students are still wanting the text-book facts, the certainties. The stories do not constitute the "real" knowledge.

S: I have also found it useful to admit students lives into the learning process, to value their history, their learning and to encourage active meaning-making. I cannot just "lecture". What would be the point? The great challenge would be to consider how new theory, especially theory which destabilises students, features in clinical training. In my experience students have been groomed into a technician mode of practice and are frequently unhappy when their routines are destabilised or challenged.

H: I feel that we will work between the old and new, and the multiplicities. I have tried to introduce life history instead of a case history as a frame for engaging with clients. Students are finding this challenging but interesting. They are learning to understand the "whole". We had a conversation about understanding the issues about stuttering within a Human Rights Framework and students were beginning to engage with it using their individual cases as a basis for discussion. I think the possibilities are interesting. The profession field has already identified the crises in the professional training in Fluency Disorders. We know that we need more Psychology to deal with the emotional aspects of therapy. However, I think it must go far beyond this. We must understand societies and people, not just disorders. Our work is about people who live in social systems.

Re-educating professions

M: I also think that the challenge is much bigger than the classroom. It is about how the profession develops and its identity. We are having our own identity crisis about

who we are and who we should be. I feel that we need to look outside the profession for creating our futures. Medicine, literature, sociology and the world at large can offer inspiration. We must engage with socio-cultural-political world realities as a means of developing ourselves.

H: I agree, but I think that the directions we take as a profession will be influenced by power and strategy. Professions will align themselves to those groupings which ensure their survival and which will promote their interests. If we had to truly collaborate with those we work with, we would not exist in our present forms, as “professionals”. I believe that there is value in multiplicity, diversity, conflict and dialogue to create “new” professional identities. I believe that it is through those conversations we can get to a better place.

In Closing ...

This conversation brought to light many issues. It was affirming to know that this offering was seen as new and different, and generated conversation about who we are and what we do. It certainly raises more questions than answers. I also recognise that the people I talked with were more partners, like-minds and there is a need for discussion with a wider audience. I feel that each reader will have his own interpretation of what I have presented. This is a good thing because my story is certainly not the first or last word in the conversation. John Berger in Roy (1997) advises that no story should be told as if it is the only one, and I invite others to continue this conversation.

REFERENCES

- Abma, T.A. 2002, 'Emerging narrative forms of knowledge representation in health sciences. Two texts in the postmodern context', *Qualitative Health Research*, vol.12, no. 1, pp. 5-27.
- Adams, M.A. 1992, 'Childhood stuttering under "positive" conditions', *American Journal of Speech-Language Pathology: A Journal of Clinical Practice*, vol.1, no. 1, pp 5-6.
- Adams, S., Pill, R & Jones, A. 1997, 'Medication, Chronic illness and Identity: The perspective of people with asthma', *Social Science & Medicine*, vol. 45, no. 2, pp 189-201.
- African National Congress, 1994, *National Health Plan*, ANC, Pretoria.
- Ahern, K.J., 1999, 'Ten tips for reflexive bracketing', *Qualitative Health Research*, vol. 9, no. 3, pp. 407-411.
- Alvesson, M. & Skoldberg, K. 2000, *Reflexive Methodology. New vistas for qualitative research*, Sage Publications, London.
- Amir, O & Yairi, E. 2002, 'The effect of temporal manipulation on the perception of disfluencies as normal or stuttering', *Journal of Communication Disorders*, vol. 35, no. 1, pp. 63-82.
- Anderson, K. & Jack, D.C. 1991, 'Learning to listen. Interview techniques and analyses', in *Women's Words. The feminist practice of oral history*, eds S.B. Gluck & D. Patai, Routledge, New York.
- Angen, M.J. 2000, 'Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue', *Qualitative Health Research*, vol. 10, no. 3, pp. 378-395.
- Antoinette, E. 2000, But Sometimes You're Not Part of the Story. *Educational Research Online* 29, 2. <http://www.aera.net/pubs/er/arts/29-02/errant02.htm>.
- Archer, M. 1995, *Realist Social Theory: The Morphogenetic Approach*, Cambridge Press, Cambridge.
- Armstrong P.F. 1987, *Qualitative Strategies in Social and Educational Research: The Life History in Theory and Practice*, University of Hull.
- Arndt, J. & Healey, E.C. 2001, 'Concomitant disorders in school-age children who stutter', *Language, Speech and Hearing Services in Schools*, vol.32, no. 2, pp 68-78.
- Aron, M.L. 1962, 'The nature and incidence of stuttering among a Bantu group of school-going children', *Journal of Speech and Hearing Disorders*, vol. 27, no. 6, pp. 1116-1128.
- Atkinson, R. 1997, *The Life Story Interview*, Sage Publications, California

Baker, B., Ross, E. & Girson, J. 1997, 'Attitudes of a Group of South African Speech-Language Pathologists Towards Stutterers and Stuttering Therapy', *The South African Journal of Communication Disorders*, vol. 44, no. 1, pp. 13-23.

Bakhtin, M.M. 1981, *The Dialogical Imagination*, University of Texas Press, Austin, TX.

Bakhtin, M.M. 1984, *Problems of Dostoyevsky's poetics*. Manchester, University Press, Manchester, UK.

Barasch, C.T., Guitar, B. Mc Cauley, R.J. & Absher, R.G. 2000, 'Disfluency and time perception', *Journal of Speech, Language and Hearing Research*, vol. 43, no. 6, pp. 1429-1439.

Barnes, C., Mercer, G. & Shakespeare, T. 1999, *Exploring Disability*, Polity Press, UK.

Barone, T.E. 1997, 'Among the chosen: A collaborative educational (auto)biography', *Qualitative Inquiry*, vol. 3, no. 2, pp. 222-236.

Barone, T.E. 2001, 'Pragmatizing the Imaginary: using life narratives as fiction', *Annual Meeting of the American Educational Research Association*, Sec 44.28: The Educated Imagination: Fiction and Knowledge.

Barresi, J. 2002, 'From 'the Thought is the Thinker' to 'the Voice is the Speaker''. William James and the Dialogical Self, *Theory & Psychology*, vol. 12, no 2, pp 237-250.

Barrow, R. 2000, 'Hearing the Story: Can narrative theory be applied to aphasia therapy to inform and guide content as well as tracking change?', *RCSLT Bulletin*, pp. 8-10.

Bateson, M.C. 1989, *Composing a life*. Atlantic Monthly Press, New York.

Bauman, Z. 2001, 'Identity in the globalising world', *Social Anthropology* vol.9, no.2, pp. 121-129.

Becker, G. 1997, *Disrupted lives: How people create meaning in a chaotic world*, University of California Press, California.

Beecham, R. 2002, A failure of care: A story of a South African Speech & Hearing Therapy student, Doctoral thesis, University of Durban-Westville, South Africa.

Bendle, M.F. 2002, 'The crisis of "identity" in high modernity', *British Journal of Sociology*, vol 53, no. 1, pp.11-18.

Bhaskar, R. 1989, *Reclaiming Reality: A Critical Introduction to Contemporary Philosophy*, Verso, London.

Blood, G.W. 1993, 'Treatment efficacy in adults who stutter: Review and recommendations', *Journal of Fluency Disorders*, vol. 18, no. 2-3, pp. 303-318.

Blood, G.W. & Blood, I.M., 1989, 'Multiple data analyses of dichotic listening advantages of stutterers', *Journal of Fluency Disorders*, vol. 14, no. 2, pp.97-107.

Blood, G.W., Blood, I.M., Tellis, G. & Gabel, R. 2001, 'Communication apprehension and self-perceived communication competence in adolescents who stutter', *Journal of Fluency Disorders*, vol. 26, no. 3, pp 161-178.

Bloodstein, O. 1960, 'The development of stuttering: II. Developmental phases', *Journal of Speech and Hearing Disorders*, vol. 25, no. 4, pp. 366-376.

Bloodstein, O. 1993, 'Communication attitudes of school-age stutters', *Journal of Fluency Disorders*, vol. 18, no. 4, pp.403-406.

Bloodstein, O. 1995, *Handbook of Stuttering*. 5th edn, Singular Publishing Group, London.

Bloodstein, O. 2001, 'Incipient and developed stuttering as two distinct disorders resolving a dilemma', *Journal of Fluency Disorders*, vol. 26, no. 1, pp. 67-73.

Bloom, L. 1993, 'Transcription and coding for child language research: The parts are more than the whole', in *Talking Data: Transcription and coding in discourse research*, eds J.A. Edwards & M.D. Lampert, Lawrence Erlbaum, Hillsdale, NJ, pp. 149-166.

Blumenthal, D. 1999, 'Representing the Divided Self', *Qualitative Inquiry*, vol. 5, no. 3, pp 377-392.

Blumer, H. 1969, *Symbolic Interactionism: Perspective and Method*, Prentice Hall, Englewood-Cliffs, NJ.

Blumfeld-Jones, D. 1995, 'Fidelity as a criterion for practising and evaluating narrative inquiry' in *Life History and Narrative*, eds J.A. Hatch & R. Wisniewski, Palmer Press.

Bosshardt, H. 2002, 'Effects of concurrent cognitive processing on the fluency of word repetition: comparison between persons who do and do not stutter', *Journal of Fluency Disorders*, vol. 27, no. 2, pp.93-114.

Bosshardt, H. 1990, 'Subvocalization and reading rate differences between stuttering and nonstuttering children and adults', *Journal of Speech and Hearing Research*, vol. 33, no. 7, pp. 776-785.

Boehmer, E. 1995, *Colonial and Postcolonial Literature*, Oxford University Press, Oxford.

Bourdieu, P. (ed) 1999, *The weight of the world. Social suffering in contemporary society*, Polity Press, London.

Boutsen, F. 1995, 'A comparative study of stress timing of stutterers and nonstutterers', *Journal of Fluency Disorders*, vol. 20, no. 2, pp. 145-155.

Boutsen, F., Brutten, G. & Watts, C. 2000, 'Timing and Intensity Variability in the Metronomic Speech of Stuttering and Nonstuttering Speakers', *Journal of Speech, Language and Hearing Research*, vol.43, no. 2, pp. 513 -520.

Bowers, R. & Moore, K.N. 1997, 'Bakhtin, Nursing Narratives, and Dialogical Consciousness', *Advances in Nursing Science*, vol. 19, no. 3, pp. 70-77.

Brown, P. 1995, 'Naming and Framing: The Social Construction of Diagnosis and Illness', *Journal of Health and Social Behaviour*, extra edition, pp. 34-52.

Brubaker, R. & Cooper, F. 2000, 'Beyond "identity". Theory and Society', *Renewal and Critique in Social Theory*, vol. 29, no. 1, pp. 1-47.

Bruner, J. 1986, *Two Modes of Thought. Actual Minds, Possible Worlds*, Harvard University Press, Cambridge, Massachusetts.

Bruner, J. 1990. *Acts of Meaning*, Harvard University Press, Cambridge, Massachusetts.

Bruner, J 1994, 'The "remembered" self', in *The remembering self construction and accuracy in the self-narrative*, U. Neisser & R. Fivush, (eds), pp 41-54.

Brutten, G.J. & Vanryckeghem, M. 1993, 'The development of stuttering: A reply to Bloodstein', *Journal of Fluency Disorders*, vol.18, no. 4, pp. 407-410.

Burman, E. 2000, Beyond the Baby and the Bathwater: postdualistic developmental psychologies for diverse childhoods. Paper presented at the 10th Early Childhood Research Association Conference (29/08/2000- 1/9/2000) University of London.
http://www.ioe.ac.uk/conference_news/eeceraprog.html.

Bury, M. 1982, 'Chronic illness as biographical disruption', *Sociology of Health and Illness*, vol. 4, pp. 167-182.

Bury, M. 2001, 'Illness narratives: Fact or Fiction?' *Sociology of Health & Illness*, vol. 23, no. 3, pp. 263-285.

Busfield, J. 2000, 'Introduction: Rethinking the sociology of mental health', *Sociology of Health & Illness*, vol. 22, no. 3, pp. 543-556.

Campbella, C. 1997, 'Migrancy, masculine identities and AIDS: the psychosocial context of HIV transmission on the South African goldmines.' *Social Science & Medicine*, vol.45, no. 2, pp. 273-281.

Caruso, A. Ritt, C. & Somers, R. 2002, 'Interactions between fluency and phonological disorders: Case Study', *Contemporary Issues in Communication Science and Disorders*, vol. 29, no. 2, pp. 146-153.

Cary, L.J. 1999, 'Unexpected stories: Life history and the limits of representation', *Qualitative Inquiry*, vol. 5, no. 3, pp. 411-427.

Casey, K. 1995, 'The new narrative research in education', in *Review of Research in Education*, ed M. W. Apple, vol. 21, pp. 211-254.

Castells, M. 1997, *The Power of Identity*, Blackwell, Oxford.

Chanfrault-Duchet, M. 1991, 'Narrative structures, social models and symbolic representation in the life story', in *Women's words. The feminist practice of oral history*, eds S. Gluck & D. Patai, New York: Routledge, New York, pp 72-92.

Charmaz, K. 1983, 'Loss of Self. A fundamental form of suffering in the chronically ill', *Sociology of Health and Illness*, vol. 5, no. 4, pp.168-195.

- Charmaz, K. 1987, 'Struggling for a Self: Identity levels of the chronically ill'. eds In J.P. Roth, & P. Conrad, *Research in the Sociology of Health Care*. JAI Press, Greenwich,CT.
- Charmaz, K. 1995a, 'The body, identity and self. Adapting to impairment', *Sociological Quarterly*, vol. 36, no. 5, pp. 657-680.
- Charmaz, K. 1995b, 'Grounded Theory' in *Rethinking methods in Psychology*, eds J. A. Smith, R. Harre & L. Van Langenhove, Sage Publications, London pp 27-49.
- Charmaz, K. 1999, 'Stories of suffering: Subjective tales and research narratives', *Qualitative Health Research*, vol. 9, no. 3, pp 362-382.
- Charon, R. 2000, 'Literature and Medicine: Origins and Destinies', *Academic Medicine*, vol. 75, no. 1, pp. 23-27.
- Chase, S.E. 1995, 'Taking narrative seriously: Consequences for Method and Theory in Interview studies', in *Interpreting Experience. The Narrative Study of Lives*, eds R. Josselson & A. Lieblich, vol 3, 1-26, Sage Publications, London.
- Chesney, M. 2001, 'Dilemmas of self in method', *Qualitative Health Research*, vol. 11, no. 1, pp. 127-135.
- Clandinin, D J. and Connelly, F M. 1994, 'Personal Experience Methods' in *Handbook of Qualitative Research*, eds N.K. Denzin & Y. Lincoln, Sage, California, pp. 413-427.
- Clandinin, D.J. & Connelly, F.M. 2000, *Narrative inquiry. Experience and story in qualitative research*, Jossey-Bass Publishers, San Francisco.
- Colcord, R. & Gregory, H. 1987, 'Perceptual analysis and nonstuttering children's fluent speech productions', *Journal of Fluency Disorders*, vol. 12, no. 2, pp. 185-195.
- Cole, A.L. & Knowles, J.G. 2001, *Lives in Context. The art of life history research*, Walnut Creek, CA.
- Connole, H. 1993, 'The Research Enterprise,' In *Study Guide: Issues and Methods in Research*, eds H. Connole, B. Smith & R. Wiseman, University of Southern Australia, Underdale, pp. 17-42.
- Conrad, P.1987, 'The experience of illness: Recent and new directions', *Research in the Sociology of Health Care*, vol.6, no. 1, pp. 1-31.
- Conture, E. & Melnick, K. 2000, 'Relationship of length and grammatical complexity to the systematic and non-systematic speech errors and stuttering of children who stutter', *Journal of Fluency Disorders*, vol. 25, no. 1, pp. 21-25.
- Cooper, E.B. 1987, 'The chronic perseverative stuttering syndrome; Incurable stuttering', *Journal of Fluency Disorders*, vol. 12, no. 6, pp. 381-388.
- Cooper, E.B. & Cooper, C.S. 1996, 'Clinical attitudes towards stuttering: Two decades of change'. *Journal of Fluency Disorders*, vol. 21, no. 2, pp. 119-135.

Corbin, J. & Strauss, A. 1987, 'Accompaniments of chronic illness: changes in body, self, biography, and biographical time', *Research in the Sociology of Health Care*, vol. 6, no. 3, pp. 249-281.

Corcoran, J.A. and Stewart, M., 1998, 'Stories of stuttering. A qualitative analysis of interview narratives', *Journal of Fluency Disorders*, vol. 23, no. 4, pp. 247-264.

Cordes, A.K. 2000, 'Individual and consensus judgements of disfluency types in speech of persons who stutter', *Journal of Speech, Language and Hearing Research*, vol. 43, no. 4, pp. 951-964.

Cordes, A.K. & Ingham, R.J. eds. 1998, *Treatment Efficacy for Stuttering. A search for Empirical bases*, Singular Publishing Group, London.

Corker, M. 1998, *Deaf and Disabled, or Deafness Disabled?*, Open University Press, Buckingham.

Corker, M. 1999, 'Disabled transitions: negotiating identities in a prescriptive world', in *Therapy and Learning Disabilities, Advocacy, Participation and Partnership*, eds J. Swain & S. French, pp. 117-130.

Cortazzi, M. 1993, *Narrative analysis*, Falmer Press, London.

Coward, D.D. 1990, 'The lived experience of a self-transcendence in women with advanced breast cancer', *Nursing Science Quarterly*, vol. 3, no. 2, pp. 162-169.

Cox, N.J., Seider, R.A., & Kidd, K.K., 1984, 'Some environmental factors and hypotheses for stuttering in families of several stutterers', *Journal of Speech and Hearing Research*, vol. 27, no. 4, pp. 543-548.

Craig, A. 1998, 'Relapse following treatment for stuttering: A critical review and correlative data', *Journal of Fluency Disorders*, vol. 23, no. 1, pp. 1-30.

Craig, A.R. & Calver, R. 1991, 'Following up on treated stutters: Studies of perceptions of fluency and job status', *Journal of Speech and Hearing Research*, vol. 34, no. 2, pp. 279-284.

Craig, A.R. & Hancock, K. 1995, 'Self-reported factors related to relapse following treatment for stuttering', *Australian Journal of Human Communication Disorders*, vol. 23, no. 1, pp. 48-60.

Crenshaw, C. 1997, 'Women in the Gulf War: Towards an intersectional rhetorical criticism', *Howard Journal of Communication*, vol. 19, no. 2, pp. 219-235.

Creswell, J.W. & Miller, D. L. 2000, 'Determining validity in qualitative inquiry', *Theory into Practice*, vol. 39, no. 3, pp. 124-130.

Crichton-Smith, I. 2002, 'Communicating in the real-world: accounts from people who stammer', *Journal of Fluency Disorders*, vol. 27, no. 4, pp. 333-352.

Crocker, J., Major, B. & Steele, C. 1998, 'Social Stigma', in *Handbook of Social Psychology*, 4th ed, eds D.T. Gilbert., S.T. Fiske, & G. Lindzey, vol. 2, pp. 504-553.

Cross, D.E. & Olson, P.L. 1987, 'Articulatory-laryngeal interaction in stutters and normal speakers: effects of a bite-block on rapid voice initiation', *Journal of Fluency Disorders*, vol. 12, no. 6, pp. 407-418.

De Nil, L., Houle, S., Kapur., & Kroll, R. 2000, 'A positron emission tomography study of silent and oral single word reading in stuttering and nonstuttering adults', *Journal of Speech, Language and Hearing*, vol. 3, no. 8, pp. 1038-1053.

Denny, M. & Smith, A. 1992, 'Gradation in pattern of neuromuscular activity associated with stuttering', *Journal of Speech and Language Research*, vol. 35, no. 6, pp. 1216-1229.

Denzin, N.K. 1995, *The Cinematic Society: The Voyeur's Gaze*, Sage Publications, London.

Denzin, N.K. 1997, *Interpretive Ethnography: Ethnographic practices for the 21st Century*, Sage Publications, London.

Denzin, N.K. 2000, 'Aesthetics and the practices of qualitative inquiry', *Qualitative Inquiry*, vol. 6, no. 2, pp. 256-265.

Denzin, N.K. & Lincoln, Y.S. 1994, 'Introduction: Entering the field of qualitative research', in *Handbook of Qualitative Research*, eds N.K. Denzin, & Y.S. Lincoln, Sage Publications, Thousand Oaks, CA, pp. 1-18.

Denzin, N.K. & Lincoln, Y.S. 1998, *The Landscape of Qualitative Research. Theories and Issues*, Sage Publications, California.

Department of Health, 2000a, *Rehabilitation for All: National Rehabilitation Policy*, South African Government Publishers, Pretoria, South Africa.

Department of Health, 2000b, *Primary Health Care Package for South Africa: A Set of Norms and Standards*, South African Government Publishers, Pretoria, South Africa.

Desai, A. 2000, *The Poors of Chatsworth*, Madiba Publishers, South Africa.

Dhunpath, R. 2000, 'Life history methodology: "narradigm" regained', *Qualitative studies in Education*, vol. 13, no. 5, pp. 543-551.

Dhunpath, R. 2002, Institutional biographies an empowerment evaluation, paper presented at Symposium on Life History Research, Advances in Qualitative Methods Conference, Sun City, South Africa, January.

Dietrich, S., Jensen, K.H., & Williams, D.E. 2001, 'Effects of the label "stutterer" on student perceptions', *Journal of Fluency Disorders*, vol. 26, no. 1, pp 55-66.

Dildy, S.M.P. 1996, 'Suffering in people with rheumatoid arthritis', *Applied Nursing Research*, vol. 9, no. 2, pp. 177-183.

Dilollo, A., Manning, W. & Neimeyer, R. 2002, 'A personal construct psychology view of relapse: indications for a narrative component to stuttering treatment', *Journal of Fluency Disorders*, vol. 27, no. 1, pp. 19-42.

- Drayna, D. 1997, 'Genetic linkage studies of stuttering: Ready for Prime Time?' *Journal of Fluency Disorders*, vol. 22, no. 3, pp. 237-241.
- Drummond, N. 2000, 'Quality of life with asthma: the existential and aesthetic', *Sociology of Health and Illness*, vol. 22, no. 3, pp. 235-255.
- Easton, K.L. & Fry, J. 2000, 'Avoiding common pitfalls in qualitative data collection and transcription', *Qualitative Health Research*, vol. 10, no. 5, pp. 703-707.
- Ebbs, C.A. 1996, 'Qualitative research inquiry: issues of power and ethics', *Education*, Chula Vista, California, vol. 117, pp. 217-222.
- Ely, R. 1995, 'The power of demography: women's social constructions of gender identity at work', *Academic Management Journal*, vol. 38, no. 4, pp.589,634.
- Erikson, E.H. 1959, 'Identity and the life cycle: Selected papers', *Psychological Issues*, vol. 1, no. 1, pp.1-171.
- Erikson, E.H. 1968, *Identity: Youth and Crisis*, Faber, London.
- Fairclough, N. 1989, *Language and Power*, Longman, London
- Fay, B. 1996, *Contemporary Philosophy of Social Science. A Multicultural Approach*, Blackwell Publishers, Oxford, pp. 178-245.
- Fine, M. 1998, 'Working the hypens: Reinventing Self and Other in Qualitative Research', in *The landscape of Qualitative research. Theories and Issues*, eds N.K. Denzin & Y.S. Lincoln, Sage Publications, London.
- Finn, P. & Cordes, A.K. 1994, 'Multicultural identification and treatment of stuttering: A continuing need for research', *Journal of Fluency Disorders*, vol. 22, no. 4, pp. 219-232.
- Flick, U. 1999, *An introduction to Qualitative Research*, Sage Publications, London.
- Fontana, A. & Smith, R.W. 1989, 'Alzheimer's disease victims: The unbecoming of self and normalisation of competence', *Sociological Perspectives*, vol. 32, no. 1, pp. 35-46.
- Foucault, M. 1976, *The Birth of the Clinic: An Archaeology of Medical Perception*, Tavistock, London.
- Foucault, M. 1977, *Discipline and Punish*, Allen Lane, London.
- Foucault, M. 1980, *Power/Knowledge: Selected interviews and Other Writings*, Panthenon, New York.
- Fowlie, G.M. & Cooper, E.B. 1978, 'Traits attributed to stuttering and nonstuttering children by their mothers', *Journal of Fluency Disorders*, vol. 3, no. 4, pp. 233-246.
- Frank, A.W. 1995, *The Wounded Storyteller: Body, Illness and Ethics*, Chicago University Press, Chicago.
- Frank, A.W. 1997, 'Illness as moral occasion restoring agency to ill people', *Health*, vol. 1, no. 2, pp. 131-148.

Frank, A.W. 2000a, 'The Standpoint of Storyteller', *Qualitative Health Researcher*, vol. 10, no. 3, pp. 354-365.

Frank, A.W. 2000b, 'Illness and the interactional vocation', *Symbolic interaction*, vol. 23, no. 4, pp. 321-332.

Frank, A.W. 2001, 'Can we research suffering', *Qualitative Health Research*, vol. 11, no. 3, pp. 353-362.

Frank, A.W. 2002, Narrative Analysis. Why Study People's Stories? The Dialogical Ethics of Narrative Analysis. *International Journal of Qualitative Methods*. <http://www.ualberta.ca/~ijqm/>

Frank, G. 2000, *Venus on wheels. Two decades of dialogue on disability, biography and being female in America*, University of California Press, California.

Freeman, D. 1996, ' "To Take Them at their Word": Language Data in the study of Teacher's Knowledge', *Harvard Educational Review*, vol. 66, no.4, pp. 732-761.

Freeman, F. 1999, Going out on a limb. Hypothesis regarding the Nature and Treatment of Stuttering. Paper presented at the International Stuttering Awareness Day Conference, <http://www.mankato.msus.edu/dept/comdis/isad/papers/html>.

Freitas, A., Kaiser, S., Chadler, J., Hall, C., Kim, J.W. & Hammidi, T. 1997, 'Appearance management as border construction: leas favourite clothing, group distancing, and identity-not!', *Sociological Inquiry*, vol. 67, no. 2, pp. 323-335.

Freund, P.E. 1988, 'Bringing society into the body', *Theory and Society*, vol. 17, no. 3, pp. 839-864.

Gadow, S. 1990, 'Response to "Personal Knowing: evolving research and practice"' *Scholarly Inquiry in Nursing Practice*, vol. 4, no. 1, pp. 167-170.

Garro, L.C. 1994, 'Narrative Representations of Chronic Illness Experience: Cultural Models of Illness, Mind and Body in Stories Concerning the Temporomandibular Joint (TMJ)', *Social Science & Medicine*, vol. 38, no. 6, pp. 775-788.

Gergen, K.J. 1994a, *Realities and Relationships*, Harvard University Press, Cambridge.

Gergen, K.J. 1994b, 'Mind, text and society: Self-memory in social context', in *The remembering self : Construction and accuracy in the self-narrative*, eds U. Neisser & R. Fivush, pp 78-104.

Gerhardt, U. 1989, *Ideas about illness: An intellectual and political history of medical sociology*, London: Macmillan.

Giddens, A. 1991, *Modernity and Self-identity: Self and Society in the late Modern age*, Polity Press, Cambridge.

Glaser, B.G. & Strauss, A. L. 1967, *The Discovery of Grounded Theory. Strategies for Qualitative Research*. Aldine Publishing Company, Chicago.

Goffman, E. 1963, *Stigma*, Prentice-Hall, Englewood-Cliffs, NJ.

- Goffman, E. 1967, *Interaction Ritual*, Doubleday-Anchor, Garden City, New York.
- Good, B.J. & Good, M.D. 1994, 'In the Subjunctive Mode: Epilepsy Narratives in Turkey', *Social Science & Medicine*, vol. 38, no. 6, pp. 835-842.
- Good, M.D., Munakata, T., Kobayashi, Y., Mattingly, C. & Good, B.J., 1994, 'Oncology and Narrative Time', *Social Science & Medicine*, vol. 38, no. 6, pp. 855-862.
- Goodson, I.F. 1992, *Studying teacher's lives*, Routledge, London.
- Goodson, I.F. 1995, 'The story so far: personal knowledge and the political', in *Life History and Narrative*, eds J.A. Hatch & R. Wisniewski, Falmer Press, London.
- Gordon, N.S. 2000, Researching Psychotherapy, the Importance of the Client's View: A Methodological Challenge. The Qualitative Report 4, 3 & 4. <http://www.nova.edu/ssw/QR/QR4-3/gordon.html>.
- Gough, N., 2001, Exploring elements of life history research, Doctoral seminar presentation at the University of Durban-Westville, South Africa, July.
- Green, T. 1999, 'The relationship of self-conception to perceived stuttering severity in children and adults who stutter', *Journal of Fluency Disorders*, vol. 24, no. 4, pp. 281-292.
- Greenhalgh, T. 1999, 'Narrative based medicine in an evidence based world', *British Medical Journal*, vol. 318, no. 4, pp. 323-325.
- Greenhalgh, T. & Hurwitz, B. 1999, 'Narrative based medicine. Why Study Narrative?', *British Medical Journal*, vol. 318, no. 1, pp. 48-50.
- Guba, E.G. & Lincoln, Y.S. 1998, 'Competing Paradigms in Qualitative Research', in *The Landscape of Qualitative Research*, eds N.K. Denzin & Y.S. Lincoln, Sage, Thousand Oaks, CA.
- Guitar, B. 1998, *Stuttering. An Integrated Approach to its Nature and treatment*, 2nd edn, Williams & Wilkins, London.
- Guitar, B., Guitar, C., Neilson, P., O'Dwyer, N. & Andrews, G. 1998, 'Onset sequencing of selected lip muscles in stutterers and nonstutterers', *Journal of Speech and Hearing Research*, vol. 31, no. 1, pp. 28-35.
- Guitar, B. & Marchinkoski, L. 2001, 'Influence of mothers slower speech on their children's speech rate', *Journal of Speech, Language and Hearing Research*, vol. 44, no. 4, pp. 853-861.
- Guitar, B., Schaefer, H., Donahue-Kilburg, G. & Bond, L. 1992, 'Parental verbal interactions and speech rate: A case in stuttering', *Journal of Speech and Hearing Research*, vol. 35, no. 5, pp. 742-754.
- Hahn, R.A. 1995, *Sickness and healing. An anthropological perspective*, Yale University Press, New haven.

Hall, K.D., Amir, O., & Yairi, E. 1999, 'A longitudinal investigation of speaking rate in preschool children who stutter', *Journal of Speech, Language and Hearing Research*, vol. 42, no. 6, pp. 1367-1377.

Hall, S. 1996, 'Introduction: Who needs identity', in *Questions of Cultural Identity*, eds S. Hall & P. du Gay, Sage, London.

Ham, R.E. 1990, 'What is stuttering: Variations and stereotypes', *Journal of Fluency Disorders*, vol. 15, no. 5 / 6, pp. 259-273.

Harrison, J.C. 1997, 'Zen in the art of fluency', *Journal of Fluency Disorders*, vol. 22, no. 4, pp. 243-246.

Harry, B. 1996, 'These families, Those families. The impact of researcher identities on the research act', *Exceptional Children*, vol. 62, no. 4, pp. 292-300.

Hatch, J.A. & Wisniewski, R. 1995, 'Life history and narrative: questions, issues and exemplary works', in *Life History and Narrative*, eds J.A. Hatch and R. Wisniewski, Falmer Press, London.

Hayhow, R., Cray, A. & Enderbury, P. 2002, 'Stammering and therapy views of people who stammer', *Journal of Fluency Disorders*, vol. 27, no. 1, pp. 1-17.

Hegde, M.N. 1998, *A Course book on Scientific and Professional Writing for Speech-Language Pathology*, 2nd edn, Singular Publishing Group, London.

Henderson, A. 1994, 'Power and knowledge in nursing practice: the contribution of Foucault', *Journal of Advanced Nursing*, vol. 20, no. 11, pp. 935-939.

Hermans, H.J.M. 2002, 'The Dialogical Self as a Society of Mind', *Theory & Psychology*, vol. 12, no. 2, pp. 252-158.

Howard, J.A. 2000, 'Social psychology of identities', *Annual Review of Sociology*, vol. 26, pp. 367-393.

hooks, b. 1989, *Talking Back: Thinking Feminist, Thinking Black*, Sheba Feminist Publishers, London.

Hugh-Jones, S. & Smith, P.K. 1999, 'Self-reports of short and long-term effects of bullying on children who stammer', *British Journal of Educational Psychology*, vol. 69, no. 3, pp. 141-158.

Hunter, K.M. 1991, *Doctors' Stories. The Narrative Structure of Medical Knowledge*, Princeton University Press, New Jersey.

Hyden, Lars-Christer 1997, 'Illness and Narrative', *Sociology of Health and Illness*, vol. 19, no. 1, pp. 48-69.

Jezer, M. 1997, *Stuttering: a life bound in words*, Basic Books, New York.

Josselson, R. 1995, 'Imagining the real: Empathy, Narrative and the Dialogic Self', in *Interpreting Experience. The Narrative Study of Lives*, vol. 3, eds R. Josselson & A. Lieblich, Sage Publications, London, pp. 27-44.

Josselson, R. 1996, *Revising herself: The story of women's identity from college to midlife*, Oxford University Press, New York.

Kalinowski, J., Stuart, A. & Armson, J. 1996, 'Perceptions of stutterers and nonstutterers during speaking and nonspeaking situations', *American Journal of Speech-Language Pathology*, vol. 2, no. 1, pp. 61-67.

Kalveram, U.N.J.G.T. 2001, 'Fluency, fundamental frequency, and speech rate under frequency-shifted auditory feedback in stuttering and nonstuttering persons', *Journal of Fluency Disorders*, vol. 26, no. 3, pp. 227-241.

Kathard, H. 2001, 'Sharing stories: life history narratives in stuttering research', *International Journal of Language and Communication Disorders*, vol. 36, Special Supplement, pp. 52-57.

Kathard, H. 2002, 'Why we may fail multicultural practice', *Perspectives on Communication Disorders in Culturally and Linguistically Diverse Populations*, vol. 8, no. 2, pp. 11-13.

Kelly, E.M. 1993, 'Speech rates and turn-taking behaviours of children who stutter and their parents', *Seminars in Speech and Language*, vol. 14, no. 3, pp. 203-211.

Kelly, E.M. & Conture, E.G. 1992, 'Speaking rates, response time latencies, and interrupting behaviours of young stutterers, nonstutterers, and their mothers', *Journal of Speech and Hearing Research*, vol. 35, no. 13, pp. 1256-1267.

Kelly, E.M., Smith, A. & Goffman, L. 1995, 'Orofacial muscle activity of children who stutter: A preliminary study', *Journal of Speech and Hearing Research*, vol. 38, no. 11, pp. 1025-1036.

Kelly, M. & Dickenson, H. 1997, 'The narrative of self in autobiographical accounts of illness', *The Sociological Review*, vol. 45, no. 2, pp. 254-278.

Kelly, M.P. & Field, D. 1996, 'Medical Sociology. Chronic illness and the body', *Sociology of Health and Illness*, vol. 18, no. 2, pp. 241-257.

Kent, B A, Furlonger, B E and Goodrick, D A (2001) Toward an Understanding of Acquired Hearing Loss in a Family: Narrative Play Format as a New Voice in Qualitative Methodology. *The Qualitative Report* 6, 4.
<http://www.nova.edu/ssss/QR/QR6-4/furlonger.html>.

Kerr, N. & Lacelle, B. 2000, 'Therapy for Aphasia: Insiders' Points of View', *Journal of Medical Speech Language Pathology*, vol. 8, no. 2, pp. 103-131.

Kitwood, T. 1993, 'Towards the reconstruction of organic mental health disorder', in *The Worlds of Health and Illness. Biographical and cultural perspectives on health and disease*, ed A. Radley, Routledge, London.

Kloth, S., Jansen, P., Kraaimaat, F. & Bruten, G. 1998, Child and Mother Variables in the Development of Stuttering Among High-Risk Children: A Longitudinal Study, *Journal of Fluency Disorders*, vol. 23, no. 4, pp. 217-230.

Knudsen, T.A. 1939, 'A study of oral recitation problems of stutterers', *Journal of Speech Disorders*, vol. 4, pp. 235-239.

- Kraaimat, F.W., Vanryckhem, Van Dam-Baggen 2002, 'Stuttering and social anxiety', *Journal of Fluency Disorders*, vol. 27, no. 4, pp. 319-331.
- Krog, A. 1998, *Country of my Skull*, Random House, Johannesburg.
- Kvale, S. 1996, *InterViews: An Introduction to Qualitative Research Interviewing*, Sage, Thousand Oaks, CA.
- Langevin, M. & Boberg, E. 1996, 'Results of intensive stuttering therapy with adults who clutter and stutter', *Journal of Fluency Disorders*, vol. 21, no. 3 / 4, pp.315-327.
- Langevin, M., Bortnick, K., Hammer, T. & Wiebe, E. 1998, 'Teasing/Bullying experienced by children who stutter: Toward development of a questionnaire', *Contemporary issues in Communication Science and Disorders*, vol. 25, no. 1, pp. 12-24.
- Langlois, A., Hanrahan, L.L. & Inouye, L.L. 1986, 'A comparison of interactions between stuttering children, nonstuttering children, and their mothers' *Journal of Fluency Disorders*, vol. 11, no. 3, pp. 263-273.
- Lanner, J. 1999, 'A Narrative Approach to Mental Health in General Practice', *British Medical Journal*, vol. 318, no. 1, pp. 117-118.
- Lapadat, J.C. & Lindsay, A.C. 1999, 'Transcription in research and practice: From standardization of technique to interpretive positionings', *Qualitative Inquiry*, vol. 5, no. 1, pp. 64-86.
- Larson, C.L. 1997, 'Re-presenting the subject: problems in personal narrative inquiry', *International Journal of Qualitative Studies in Education*, vol. 10, no. 4.
- Lass, N.J., Dennis, M., Pannbacker, M., Schmitt, J.F., Middleton, G. & Schweppenheiser, K. 1995, 'The perceptions of stutterers by people who stutter', *Folia Phonaitrica et Logopaedica*, vol. 47, pp. 247-251.
- Lather, P. 1991, *Getting smart. Feminist Research and Pedagogy with/in the Postmodern*, Routledge, New York.
- Lather, P. 1992, 'Postmodernism and the human sciences', in *Psychology and Postmodernism*, ed S. Kvale, Sage Publications, London.
- Lather, P. 2000, 'Paradigm talk revisited. How else might we characterise the proliferation of research perspectives within our field', AERA, New Orleans.
- Lather, P. 2001, 'The possibilities for paradigm proliferation', Doctoral Seminar Series, University of Durban-Westville, South Africa, November.
- Lawrence-Lightfoot S. & Hoffman-Davis, J. 1997, *The art and science of portraiture*, Jossey-Bass, San Francisco.
- Leahy, M.M. 1994, 'Attempting to ameliorate student therapists' negative stereotypes of the stutterer', *European Journal of Disorders of Communication*, vol. 29, no. 1, pp. 39-49.
- Lebrun, Y. 1998, 'Clinical observations and experimental research in the study of stuttering', *Journal of Fluency Disorders*, vol. 23, no. 1, pp. 119-122.

- Leder, D. 1992, 'A tale of two bodies: the Cartesian corpse and the lived body', in *The Body in Medical Thought and Practice*, ed D. Leder, Kluwer Academic, Dordrecht.
- Lee, C.S. 2001, 'The use of Narrative in Understanding how cancer affects development: The Stories of One Cancer Survivor', *Journal of Health Psychology*, vol. 6, no. 3, pp. 283-293.
- Lewis, P.J. 2001, 'A Story of I and the Death of a Subject', *Qualitative Health Inquiry*, vol. 7, no. 1, pp. 109-128.
- Lincoln, Y.S. & Guba, E.G. 1985, *Naturalistic Inquiry*, Sage, Beverly Hills, California.
- Lincoln, M. & Onslow, M. 1997, 'Long-term outcome of early intervention for stuttering', *American Journal of Speech-Language Pathology*, vol. 1, no. 1, pp. 51-58.
- Lindsay, J.S. 1989, 'Relationship of developmental disfluency and episodes of stuttering to the emergence of cognitive stages in children', *Journal of Fluency Disorders*, vol. 14, no. 4, pp. 271-284.
- Logan, K.J. 2001, 'The effect of syntactic complexity upon the speech fluency of adolescents and adults who stutter', *Journal of Fluency Disorders*, vol. 26, no. 1, pp. 85-106.
- Lucius-Hoene, G. & Depperman, A. 2000, 'Narrative identity empiricized: A Dialogical and Positioning approach to autobiographical research interviews', *Narrative Inquiry*, vol. 10, no. 1, pp. 199-222.
- Lysaker, P.H. & Lysaker, J.T. 2002, 'Narrative Structure in Psychosis. Schizophrenia and Disruptions in the Dialogical Self', *Theory & Psychology*, vol. 12, no. 2, pp. 207-217.
- Maharaj, M. 2001, 'Where Though Remained Unprisoned', in *Reflections in Prison*, ed M. Maharaj, Zebra, Cape Town.
- Mallard, A. R. 1998, 'Using Problem-Solving Procedures in Family Management of Stuttering', *Journal of Fluency Disorders*, vol. 2, pp. 127-135.
- Manning, W.H. 1996, *Clinical decision making in the Diagnosis and Treatment of Fluency Disorders*, Delmar Publishers, Boston.
- Marotta, V. 2002, 'Zygmunt Bauman: Order, Strangerhood and Freedom', *Thesis Eleven*, No.7, pp. 36-54.
- Mathews, H.F., Lannin, D.R. & Mitchell, J.P. 1994, 'Coming to terms with advanced breast cancer: Black women's narratives from Eastern North Carolina', *Social Science & Medicine*, vol. 38, no. 6, pp. 789-800.
- Mathieson, C.M. & Stam, H. 1995, 'Regotiating identity: Cancer narratives', *Sociology of Health and Illness*, vol. 17, no. 3, pp. 283-306.
- Mattingly, C. 1994, 'The concept of therapeutic 'emplotment'', *Social Science & Medicine*, vol. 38, no. 6, pp. 811-822.

- Mavor, A.H. 1998, 'Mouth Piece', *United Airlines Inflight Hemisphere Magazine*, March 1998.
- Mbeki, T. 1998, African Renaissance Statement. By Deputy President, Gallagher Estate, 13 August 1998. www.anc.org/ancdocs/history/mbeki/1998.
- McAdams, D. 1993, *The Stories We Live By: Personal Myths and the Making of the Self*, Guildford, Press, New York.
- McDonough, A.N. & Quesal, R.W. 1998, 'Locus of control orientation of stutterers and nonstutterers', *Journal of Fluency Disorders*, vol. 13, no. 1, pp. 97-106.
- McGraw, P.C. 2001, *Self Matters*, Simon & Schuster, London.
- McMillan, J.H. & Schumacher, S. 2001, *Research in Education: A Conceptual Introduction*, 5th edn, Addison Wesley Longman, New York.
- Mead, G.H. 1934, *Mind, Self, Society*, University of Chicago Press, Chicago.
- Measor, L. & Sikes, P. 1992, 'Visiting lives. Ethics and methodology in life history, in *Studying Teachers' lives*, ed I.F. Goodson, Teachers College Press, New York, pp.209-233.
- Mergenthaler, D. 2000, 'Oliver Sacks-A Neurologist explores the lifeworld', *Medicine, Health Care and Philosophy*, vol. 3, no. 1, pp. 177-185.
- Meyerhoff, B. & Ruby, J. 1992, 'A crack in the mirror. Reflexive practices in anthropology', in *Remembered lives: the work of ritual, storytelling and growing older*, ed M. Kaminsky, University of Michigan Press, Ann Arbor, pp. 305-360.
- Meyers, S.C. & Freeman, F.J. 1985, 'Mother and child speech rates as a variable in stuttering and disfluency', *Journal of Speech and Hearing Research*, vol. 28, no. 3, pp. 436-444.
- Miles, M.B. & Huberman, A.M. 1994, *Qualitative Data Analysis. An Expanded Sourcebook*, 2nd edn, Sage Publications, California.
- Miles, S. & Ratner, N.B. 2001, 'Parental language input to children at stuttering Onset', *Journal of Speech, Language and Hearing Research*, vol. 44, pp. 1116-1130.
- Mills, C.W. 1959, *The Sociological Imagination*, Oxford University Press, New York.
- Mishler, E.G. 1989, 'Critical perspectives on the biomedical model', in *Perspectives in Medical Sociology*, ed P. Brown, Wadsworth, Belmont.
- Mishler, E.G. 1992, 'Work, Identity and Narrative: An artist-craftsman's story', in *Storied lives. The cultural politics of self-understanding*, eds Rosenwald & R.L. Ochsberg, Yale University Press, New Haven, CT, pp. 21-40.
- Mishler, E.G. 1996, 'Missing persons. Recovering developmental stories, histories', in *Ethnography and Human Development: Context and meaning in Social inquiry*, eds R. Jessor, A. Colby, & R.A. Schweber, University of Chicago Press, Chicago, pp. 73-99.

Mishler, E.G. 1999, *Storylines. Craftartists Narratives of Identity*, Harvard University Press, London.

Morse, J.M. 1997, 'Responding to Threats to Integrity of Self', *Advances in Nursing Science*, vol. 19, no. 4, pp. 21-36.

Mowrer, D.E. 1998, 'Alternative research strategies for the investigation of stuttering', *Journal of Fluency Disorders*, vol. 23, no. 1, pp. 89-97.

Murphy, W. & Quesal, R. 2002, 'Strategies for addressing bullying with the school-age child who stutters', *Seminars in Speech and Language*, vol. 23, no. 2, pp. 205-211.

Nochi, M. 2000, 'Reconstructing Self-Narratives in Coping with traumatic Brain Injury', *Social Science & Medicine*, vol. 51, no. 12, pp. 1794 -1804

Nussbaum, M.C. 2001, *Upheavals of Thought. The Intelligence of Emotions*, Cambridge University Press, New York.

Office of Deputy President, Thabo Mbeki, November 1997, *White Paper on an Integrated National Disability Strategy*, Republic of South Africa. Pretoria.

Okri, B. 1997, *A Way of Being*, Phoenix House, London.

Oliver, M. 1990, *The Politics of Disablement*, MacMillan, Basingstoke.

Oliver, M. 1996, *Understanding Disability: from Theory to Practice*, Macmillan, London.

Orona, C.J. 1990, 'Temporality and identity loss due to Alzheimer's disease.' *Social Science and Medicine*, vol. 30, no. 12, pp. 1247-1256.

Pamphilon, B. 1999, 'The Zoom Model: A Dynamic Framework for the analysis of life histories', *Qualitative Inquiry*, vol. 5, no. 3, pp. 393-410.

Parr, S., Byng, S., Gilpin, S., & Ireland, C. 1997, *Talking about Aphasia*, Open University Press, Milton Keynes, UK.

Patton, M.Q. 1990, *Qualitative Evaluation and Research methods*, 2nd edn, Sage, London.

Pellowski, M.W., & Conture, E.G. 2002, 'Characteristics of speech dysfluency and stuttering behaviors in 3- and 4-year-old children', *Journal of Speech, Language and Hearing Research*, vol. 45, no. 1, pp. 20-23.

Perkins, W.H. 1983. 'Learning from negative outcomes in stuttering therapy II: An epiphany of failure', *Journal of Fluency Disorders*, vol. 8, no. 2, pp. 155-160.

Perkins, W.H. 1996, *Stuttering and Science*, Singular Publishing Group Inc, London.

Perkins, W.H. 1997, 'Stuttering: Why science hasn't solved it' in *Nature and Treatment of Stuttering. New Directions*, 2nd edn, eds R.F. Curlee and G.M.Siegel, Allyn and Bacon, Boston.

Perkins, W.H. 2000, *Tongue Wars. Recovery from Stuttering*, Athens Press, Nevada.

Perry, J. 1996, 'Writing the Self. Exploring the Stigma of Hearing Impairment', *Sociological Spectrum*, vol. 16, no. 3, pp. 239-261.

Personal Narrative Group 1989, 'Origins', in *Interpreting Women's Lives: Feminist Theory*, ed Personal Narratives Group, Indiana University Press, Bloomington, pp. 3-16.

Peshkin, A. 1988, 'In search of one of subjectivity - one's own', *Educational Researcher*, vol. 17, no. 1, pp. 17-22.

Peshkin, A. 2001, 'Angles of Vision: Enhancing Perception in Qualitative Research', *Qualitative Inquiry*, vol. 7, no. 2, pp. 238-253.

Peters, H.G. & Starkweather, W. 1989, 'Development of stuttering throughout life', *Journal of Fluency Disorders*, vol. 14, no.5, pp.303-321.

Petrunik, M. & Shearing, C.D. 1983, 'Fragile Façade: Stuttering and the Strategic manipulation of Awareness', *Social Problems*, vol. 31, no. 2. pp. 125-136.

Pillay, M. 2001a, "'Do You Speak Practice-ese?' A Discourse of Practice for Sharing Communication', *International Journal of Language and Communication Disorders*, vol. 36, Special Supplement, pp. 351-356.

Pillay, M. 2001b, 'Cross-cultural Practice and Other Colonial Myths', *Proceedings of the International Association of Logopedics and Phoniatrists Triennial Symposium*, IALP Symposium, August 2001, Montreal, Canada.

Pillay, M. 2003, (Re) Positioning the powerful expert and the sick person: The case of communication pathology, PhD thesis, University of Durban-Westville, South Africa.

Pillay, M., Kathard, H. & Samuel, M.A. 1997, 'The Curriculum of Practice: A Conceptual Framework For Speech-Language and Audiology Practice With A Black African First Language Clientele', *The South African Journal of Communication Disorders*, vol. 44, no. 1, pp. 109-117.

Plummer, K. 1995, 'Life Story Research', in *Rethinking methods in psychology*, eds J.A. Smith, R. Harre & L. Van Langenhove, Sage Publications, London, pp. 50-63.

Plummer, K. 2001, *Documents of Life. 2. An invitation to critical humanism*, Sage Publications, London.

Polkinghorne, D.E. 1995, 'Narrative Configuration in qualitative analysis', in *Life history and narrative*, eds J.A. Hatch & R. Wisniewski, Falmer Press, London, pp. 5-23.

Polkinghorne, D.E. 1996, 'Explorations of Narrative Identity', *Psychological Inquiry*, vol. 7, pp. 363-367.

Quantz, R. 1992, 'Interpretive method in historical research: Ethnohistory reconsidered' in *The Teachers voice*, ed R. Altenbaugh, Falmer Press, Washington DC, pp. 174-190.

Quesal, R.W. 1989, 'Stuttering research. Have we forgotten the stutterer?', *Journal of Fluency Disorders*, vol. 14, no. 3, pp. 153-164.

- Quesal, R.W. 1998, What is successful stuttering Therapy? Paper presented at the International Stuttering Awareness Day conference, 1998. <http://www.mankato.msus.edu/dept/comdis/isad/papers/quesal.html>
- Quesal, R.W. 1999, "One size fits all (or: When the only tool you have is a hammer...)." Paper presented at the International Stuttering Awareness Day Conference. <http://www.mankato.msus.edu/dept/comdis/isad/papers/quesal.html>
- Quinn, A.A., Barton, J.A., & Maglivi, J.K. 1995 'Weathering the storm. Metaphors and stories of living with multiple sclerosis', *Rehabilitation Nursing Research*, vol. 4, no. 1, pp. 19-27.
- Radley, A. 1993, 'Introduction', in *Worlds of Illness. Biographical and cultural perspectives on health and disease*, ed A. Radley, Routledge, London.
- Ramig, P.R. & Wallace, M. 1987, 'Indirect and combined direct-indirect therapy in a dysfluent child', *Journal of Fluency Disorders*, vol. 1, no. 1, pp. 41-49.
- Ratner, N.B. 1993, 'Parents, children, and stuttering', *Seminars in Speech and Language*, vol. 14, no. 3, pp. 238-246.
- Reardon, N. & Reeves, L. 2002, 'Stuttering therapy in partnership with support groups: the best of both worlds', *Seminars in Speech and Language*, vol. 23, no. 3, pp. 213-218.
- Reddy, V. 2000, Life Histories of Black South African Scientists: Academic Success in an Unequal Society, PhD thesis, University of Durban-Westville, South Africa.
- Reid, P. & Comas-Diaz, L. 1990, 'Gender and ethnicity: perspectives on dual status', *Sex Roles*, vol. 22, no. 3, pp. 397-408.
- Reis, R. 2001, 'Epilepsy and Self-Identity among the Dutch', *Medical Anthropology*, vol. 9, no. 3, pp. 355-382.
- Reissman, C.K. 1990, 'Strategic uses of narrative in the presentation of Self and illness: A research note', *Social Science and Medicine*, vol. 30, no. 11, pp. 1195-2000.
- Rhodes, C. 2000, 'Ghostwriting research: Positioning the researcher in the interview text', *Qualitative Inquiry*, vol. 6, no. 4, pp 511-525.
- Richardson, L. 1992, 'The consequences of poetic representation: Writing the Other. Rewriting the Self', in *Investigating subjectivity. Research on lived experience*, eds C. Ellis & M.G Flaherty, Sage Publications, London, pp. 125-137.
- Roberts, B. 2002, *Biographical Research*, Open University Press, Buckingham.
- Robinson, I. 1990, 'Personal narratives, social careers, and medical courses: analysing life trajectories in autobiographies of people with multiple sclerosis', *Social Science and Medicine*, vol. 30, no. 11, pp. 1173-1186.
- Robinson, T.L., Jr, Crowe, T.A. 1987, 'A Comparative Study of Speech Disfluencies in Nonstuttering Black and White College Athletes', *Journal of Fluency Disorders*, vol. 12, no. 2, pp. 147-156.

- Roy, A. 1997, *The God of Small Things*, Flamingo, London.
- Roy, A. 2001, *The Algebra of Infinite Justice*, Flamingo, London.
- Rubin, H.J. & Rubin, I. 1995, *Qualitative Interviewing. The art of hearing data*, Sage Publications, London.
- Ruscello, D.M., Lass, N.J., Schmitt, J.F. & Pannbacker, M.D. 1994, 'Special educators' perceptions of stutterers', *Journal of Fluency Disorders*, vol. 19, no. 1, pp. 125-132.
- Rust, P.C. 1996, 'Managing multiple identities: Diversity among bisexual women and men', in *Bisexuality: The psychology and Politics of an Invisible minority*, ed. B.A. Firestein, Sage Publications, Thousand Oaks, CA, pp. 53-83.
- Ryan, B.P. 2001, 'A longitudinal study of articulation, language, rate and fluency of 22 preschool children who stutter', *Journal of Fluency Disorders*, vol. 26, no. 1, pp. 107-127.
- Sacks, O. 1985, *The Man who Mistook his Wife for a Hat and Other Clinical tales*, Gerald Duckworth, London.
- Sacks, O. 1990, *Awakenings*, Picador, London.
- Sacks, O. 1995, *An Anthropologist on Mars: Seven Paradoxical Tales*, Picador, London.
- Samuel, M. 1998, Words, lives and music. On becoming a Teacher of English, PhD thesis, University of Durban-Westville, South Africa.
- Samuel, M. 2001, Issues of Voice in Life History Research. Doctoral Seminar Series, University of Durban-Westville, July.
- Sarbin, T.R. 1986, 'The Narrative as a Root Metaphor for Psychology', in *Narrative Psychology: The storied nature of human conduct*, ed T.R. Sarbin, Praegar Publishers, New York.
- Schneider, J.W. & Conrad, P. 1980, 'In the closet with illness: Epilepsy, stigma potential and information control', *Social Problems*, vol. 28, no. 1, pp. 32-44.
- Seale, C. 1999, 'Quality in Qualitative research', *Qualitative Inquiry*, vol. 5, no. 4, pp. 465-478.
- Shakespeare, T. 1992, 'A response to Liz Crow'. *Coalition*, September, pp40-42.
- Shakespeare, T. 1994, 'Cultural representations of Disabled People: Dustbins for disavowal', *Disability and Society*, vol. 9, no. 3, pp. 283-303.
- Shames, G.H. 1989, 'Stuttering: An RFP for a cultural perspective', *Journal of Fluency Disorders*, vol. 14, no. 1, pp. 67-77.
- Sheehan, J.G. 1975, 'Conflict theory and avoidance reduction therapy', in *Stuttering-A second symposium*, ed Eisenson, J., Harper and Row, New York.

Sheehan, J.G. 1984, 'Problems in the evaluation of progress and outcome', in *Current Therapy of Communication Disorders: Stuttering Disorders*, ed W.H. Perkins, Thieme-Stratton, New York.

Shiffrin, D. 1994, *Approaches to Discourse*, Blackwell, Oxford.

Shiffrin, D. 1996, 'Narrative as Self-portrait: Sociolinguistic constructions of Identity', *Language in Society*, vol. 25, no. 2, pp. 167-203.

Shultz, D.A. 1991, 'Time pressure variables in the verbal parent-child interaction patterns of fathers and mothers of stuttering, phonologically disordered and normal preschool children', in *Speech motor control and stuttering*, eds H.F.M. Peters, W. Hulstijn & C.W. Starkweather, Elsevier, Amsterdam.

Silverman, E. 2001, Consumer alert: Stuttering and gender research. Paper presented at Fourth International Stuttering Awareness Day Conference, October, 2001.

<http://www.mnsu.edu/dept/comradis/isad4/papers/silverman2.html>.

Silverman, F.H. 1990, 'Are professors likely to report having "beliefs" about the intelligence of students who stutter?', *Journal of Fluency Disorders*, vol. 15, no. 5 / 6, pp. 319-321.

Silverman, F.H. & Paynter, K.K. 1990, 'Impact of stuttering on perception of occupational competence', *Journal of Fluency Disorders*, vol. 15, no. 1, pp. 87-91.

Skultans, V. 1999, 'Narratives of the body and history: illness in the judgement on the Soviet past', *Sociology of Health & Illness*, vol. 21, no. 3, pp. 310-328.

Smith, L.M. 1994, 'Biographical Method', in *Handbook of Qualitative Research Methodology*, eds N.K. Denzin & Y.S. Lincoln, Sage Publications, London, pp. 286-305.

Snyder, G.J. 2000, An Analysis of Stuttering Treatment measurements and Therapy Efficacy: Implications for a New Stuttering Therapy Paradigm. <http://www.stuttering.advocate.net/paper.html>.

Snyder, G.J. 2001, 'Exploratory research in the measurement and modification of attitudes toward stuttering', *Journal of Fluency Disorders*, vol. 26, no. 2, pp. 149-160.

Somers, M.R. 1994, 'The narrative constitution of identity: A relational and network approach', *Theory and Society. Renewal and Critique in Social Theory*, vol. 23, no. 5, pp. 604-635.

Sparkes, A.C. 1995, 'Living our Stories, Storying our Lives and the Spaces in Between: Life History Research as a Force for Change', *The Qualitative Challenge. Reflections on Educational Research*, vol. 5, no. 1, pp. 77-108.

Spence, D.P. 1986, 'Narrative smoothing and clinical wisdom', in *Narrative psychology: the storied nature of human conduct*, ed T.R. Sarbin, Praeger, New York, pp. 221-232.

Spivak, G.C. 1988, 'Can the Subaltern Speak?', in *Marxism and the Interpretation of Culture*, eds C. Nelson & L. Grossberg, University of Illinois Press, Chicago, pp. 271-313.

St. Louis, K.O. (ed.) 1986, *The Atypical Stutterer. Principles and Practices of Rehabilitation*, Academic Press, New York.

St. Louis, K.O. 2001, *Living with stuttering. Stories, basic, resources and hope*, Populore Publishers, Morgantown, W.V.

St. Louis, K.O., Lubker, B.B., Yaruss, J.S., Phil, J. & Diggs, C.C. 2001, (in press). *International Public Opinion survey of Stuttering: Pilot results*.

Starkweather, C.W. 2001, Below the surface: Treating the emotional aspects of stuttering. Paper presented at the fourth International Stuttering Awareness Day Conference.

<http://www.msu.edu/dept/comdis/isad4/papers/starkweather4.html>.

Strauss, A. 1959, *Mirrors & Masks*, Sociology Press, Mill Valley, CA.

Sue-O'Brien, D. 1993, *Stuttering. Dimensions of an unfolding experience*, PhD thesis, University of Southern California, Los Angeles.

Tetnowski, J.A. & Damico, J.S. 2001, 'A demonstration of the advantages of qualitative methodologies in stuttering research', *Journal of Fluency Disorders*, vol. 26, no. 1, pp. 17-42.

Thompson, P. 1981, 'Life histories and the analysis of social change', in *Biography and Society: The life History Approach in the Social Sciences*, ed D. Bertaux, Sage, London.

Thomson, A., Frisch, M. & Hamilton, P. 1994, 'The memory and history debates: some international perspectives', *Oral History*, Autumn, pp. 33-43.

Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G. & Jillings, C. 2002, 'Chronic illness experience. Insights from a Metastudy', *Qualitative Health Research*, vol. 2, no. 4, pp. 437-452.

Thuriaux, M.C. 1995, 'The IDICH: Evolution, status and prospects', *Disability and Rehabilitation*, vol. 17, no. 3-4, pp. 112-118.

Timmermans, S. & Gabe, J. 2002, 'Introduction: Connecting criminology and sociology of health and illness', *Sociology of Health and Illness*, vol. 24, no. 5, pp3-8.

Truth and Reconciliation Commission of South Africa 1998, *Truth and Reconciliation Commission of South Africa Report*, vol. 1, Juta and Company Ltd, Johannesburg.

Turner, B.S. 1999, *Medical Power and Social Knowledge*, 2nd edn, Sage Publications, London.

Tutu, D. 2001, 'Foreword', in *Reflections in Prison*, ed M. Maharaj, Zebra, Cape Town.

Valsiner, J. 2002, 'Forms of Dialogical Relations and Semiotic Autoregulations within the Self', *Theory & Psychology*, vol. 12, no.2, pp. 251-265.

Van Borsel, J., Maes, E. & Foulon, S. 2001, 'Stuttering and bilingualism. A review', *Journal of Fluency Disorders*, vol. 26, no. 3, pp. 179-205.

- Van Riper, C. 1973, *The Treatment of Stuttering*, Prentice Hall, Englewood Cliffs, NJ.
- Van Riper, C. 1982, *The Nature of Stuttering*, Prentice, Englewood Cliffs, NJ.
- Vanryckeghem, M. 1995, 'The Communication Attitude Test: A Concordancy Investigation of Stuttering and Nonstuttering Children and their Parents', *Journal of Fluency Disorders*, vol. 20, no. 2, pp. 191-203.
- Vanryckeghem, M. & Brutten, G.J. 1996, 'The relationship between communication attitude and fluency of stuttering and nonstuttering children', *Journal of Fluency Disorders*, vol. 21, no. 1, pp. 109-118.
- Vanryckeghem, M., Hylebos, C., Brutten, G.J., & Peleman, M. 2001, "The relationship between communication attitude and emotion of children who stutter", *Journal of Fluency Disorders*, vol. 26, no. 1, pp. 1-15.
- Wagner, J. 1993, 'Ignorance in educational research: Or, how can you not know that?', *Educational Researcher*, vol. 22, no. 5, pp. 15-23.
- Watson, J.B. 1987, 'Profiles of Stutterers' and Nonstutterers' Affective, Cognitive, and Behavioural Communication Attitudes', *Journal of Fluency Disorders*, vol. 12, no. 4, pp. 389-405.
- Watson, N. 2002, 'Well, I know this is Going to Sound very Strange to You, But I don't see Myself as a Disabled Person: identity and disability', *Disability and Society*, vol. 17, no. 5, pp.509-527.
- Williams, G. 1993, 'Chronic illness and the pursuit of virtue in everyday life' in *The worlds of Health and Illness. Biographical and Cultural Perspectives on Health and Disease*, ed A. Radley, Routledge, London.
- Williams, R. 1995, 'Personal construct theory in use with people who stutter' in *Stuttering from theory to practice*, ed M. Fawcus, Whurr Publishers, London, pp. 111-134.
- Williams, S.J. 1999, 'Is anybody there? Critical realism, chronic illness and the disability debate', *Sociology of Health & Illness*, vol. 21, no. 6, pp. 797-819.
- Williams, S.J. 2000, 'Chronic illness as biographical disruption or biographical as chronic illness? Reflections on a core concept', *Sociology of Health & Illness*, vol. 22, no. 1, pp. 40-67.
- Witherell, C. & Noddings, N. (Eds) 1991, *Stories lives tell: Narratives and dialogue in education*, Teachers College Press, New York.
- Woodward, K. 1997, 'Concepts of identity and difference', in *Identity and Difference*, ed K. Woodward, Sage Publications, London, pp. 7-62.
- World Health Organisation, 1999, *ICIDH-2: International Classification of Functioning and Disability Beta-2 Draft*, 1999, World Health Organisation, Geneva, Switzerland, July.

Wray-Bliss, E. 2002, 'Abstract Ethics, Embodied Ethics: The Strange Marriage of Foucault and Positivism in Labour Process Theory', *Organization Articles*, vol. 9, no. 1, pp. 5-39.

Yaruss, J.S. 1998, 'Describing the Consequences of Disorders: Stuttering and the International Classification of Impairments, Disabilities, and Handicaps', *Journal of Speech, Language, and Health Research*, vol. 41, no. 2, pp. 249-257.

Yaruss, J., Quesal, R.W., Reeves, L., Molt, L.R., Kluetz, B., Caruso, A.J., McClure, J.A. & Lewis, F. 2002, 'Speech treatment and support group experiences of people who participate in the National Stuttering Association', *Journal of Fluency Disorders*, vol. 27, no. 2, pp. 115-134.

Yoshida, K.K. 1993, 'Reshaping of self: a pendular construction of self and identity among adults with traumatic spinal cord injury', *Sociology of Health and Illness*, vol. 15, no. 3, pp. 217-245.

Young, K. 1989, 'Narrative embodiments: enclaves of the self in the realm of medicine', in *Texts of Identity*, eds J. Shotter & K. Gergen, Sage, London.

Zebrowski, P.M. 1993, 'Parents' judgments of children's fluency', *Seminars in Speech and Language*, vol. 14, no.3, pp. 192-200.

Zukav ,G. 2000, *Soul Stories*, Simon & Schuster, London.

APPENDIX A

SAMPLE DIAGNOSTIC REPORT AND COMMENTARY

240

C.1.4. Sample Diagnostic Reports

C.1.4. SAMPLE DIAGNOSTIC REPORT: STUTTERING

University Speech and Hearing Clinic,
Freemont University
Valleyville, California

DIAGNOSTIC REPORT

NAME: James Foxx	ASSESSMENT DATE: xx-xx-xx
BIRTHDATE: xx-xx-xx	FILE NUMBER: RS92019
ADDRESS: Graves 312 B	DIAGNOSIS: Stuttering
CITY: Valleyville, CA 90710-3342	DATE OF REPORT: xx-xx-xx
TELEPHONE NUMBER: 555-3235	INFORMANT: Self
REFERRED BY: SELF	CLINICIAN: Meena Wong

BACKGROUND AND PRESENTING COMPLAINT

James Foxx, a 21-year-old male, was seen for a speech and language evaluation at the Freemont University Speech and Hearing Clinic on February x, xxxx. He had applied for services for his stuttering after he read an article in the campus news- paper about the speech and hearing services on campus. James is a student at the university, majoring in computer science.

HISTORY

James reported that, according to what his parents have told him, his stuttering began when he was about 3 years of age. From the age of 4 through 9 years, James received treatment for his stuttering at J. R. Cronin Elementary School in Dublin, California. At age 7, he also received approximately a year of treatment at Motherlode University, Red Wing. He has not received treatment since that time. James reported that the severity of his stuttering fluctuates depending on his mood, and it is more pronounced in stressful situations.

He reports increased frequency of stuttering when he speaks to strangers, his instructors, and his father. He thinks he is less dysfluent when he speaks to his mother, brother, sister, and close friends. He said that he would rather not order at restaurants, buy tickets at counters, introduce himself, or answer telephone calls. He does not think that he has difficulty with specific words or sounds.

Family and Social History

James lives on campus. His parents live in Merced, California. He is the oldest of three children. His younger brother and younger sister do not have communication problems. He believes that his maternal uncle and his son both stutter. James is not aware of any person on his father's side who stutters.

James lives with a roommate in a dorm on the campus. He says that his verbal interactions with his roommate are limited. He has other friends with whom he spends more time. Reportedly, he has difficulty asking for dates because he is worried that he might stutter badly.

Educational and Occupational History

James had part-time jobs in various businesses. He believes that his stuttering was always a frustrating problem in the work place. He usually avoided speaking to his supervisors. He tended to seek work that did not involve much oral communication.

James is studying for a degree in computer science. He is doing well in his courses. He does not think that his stuttering has negatively affected his coursework or relationship with his instructors. He plans to work for a private company when he finishes his degree. He is concerned about being able to communicate under job pressure. James appears to be highly motivated for treatment, as he wants to be able to speak fluently.

ASSESSMENT INFORMATION***Orofacial Examination***

An orofacial examination was performed to assess the structural and functional integrity of the oral mechanism. The examination did not reveal anything of clinical significance.

Types and Frequency of Dysfluencies

To analyze the types and the frequency of dysfluencies, a conversational speech sample was recorded. James was also asked to bring an audiotaped conversational speech sample within the next 3 days. An analysis of the two samples revealed the following types and frequency of dysfluencies.

C. 1.4. Sample Diagnostic Reports

Dysfluency Types	Clinic Sample Total Words: 1231		Home Sample Total Words: 1071
	Frequency of Dysfluency	% of Total Dysfluency	Frequency of Dysfluency
Interjections	86	6.9	26
Pauses	29	2.3	9
Part-word reps	68	5.5	60
Whole-word reps	9	7	57
Audible prolongations	52	4.2	4
Silent prolongations	7	0.6	4
Revisions	8	6	6
Incomplete phrases	2	0.2	1
TOTAL	261		199
PERCENT DYS. RATE	21		18.6

Both the speech samples contained pauses from 5-25 seconds in duration. His sound and silent prolongations typically exceeded 1 sec. James's rate of speech was calculated between 10 and 150 words per minute depending on the amount and duration of pauses and prolongations. He intermittently rushed groups of words. Overall rate of speech was variable depending on amount of dysfluencies.

An occasional eye blink and hand movements associated with dysfluencies were observed during the interview. These motor behaviors were most often associated with part-word repetitions and silent and sound prolongations.

Language Production and Comprehension

An informal assessment of a 100-utterance, 1,231-word, conversational language sample revealed expressive language skills that were judged appropriate for his level of education. No language comprehension problems were noted during the interview.

Voice

James spoke with laryngeal tension and hard glottal attack approximately 50% of the time. Tension and abrupt initiation of voice were often associated with dysfluencies. Nonetheless, he exhibited appropriate vocal intensity, intonation, and inflectional patterns.

Hearing Screening

A bilateral hearing screening was administered at 25 dB HL for 250, 500, 1000, 2000, 4000, 6000, and 8000 Hz. James responded to all frequencies.

DIAGNOSTIC SUMMARY

Analysis of the conversational speech samples revealed that James FOXX exhibits a severe fluency disorder with 15 to 21% dysfluency rates. His dominant dysfluencies are repetitions, prolongations, interjections, and pauses.

RECOMMENDATIONS

It is recommended that James Foxx receive treatment for his stuttering in which the following fluency skills be taught within a fluency-shaping program:

- 1. Teaching appropriate airflow, rate reduction, and gentle phonatory onset.
- 2. Production of 98% fluent speech within the clinic.
- 3. Maintenance of at least 95% fluency in extraclinical situations.

Submitted by _____

Meena Wong, B.A.
Student Clinician

Client's signature _____

James Foxx

Approved by _____

Nancy Lopez, M.A., CCC-SLP
Speech-Language Pathologist and Clinical Supervisor

From: Hegde (1998)

Commentary on report illustrating medical influences

Case report content and structure	Issues and commentary
1. Report format : The categories/headings Background and presenting compliant Assessment information -Orofacial examination - Types and frequency of disfluency - Language production and communication	The report structure and format captures the professional and technologised language of the profession. It is interested in the problem/ disorder and uses a specific discourse/ set of terms to construct the problem : Orofacial, types of disfluency
2. Case History	The history of the stuttering disorder and treatment is captured. This is revealed in the description of the - Age of onset - Changes over time - Development of the disorder - Variable nature of the problem - Treatment The social and family history has reference to <i>stuttering</i> only. The social impact of stuttering is mentioned for the <i>individual</i> . The occupational and educational history have reference to stuttering. Hence, the case interview traces the history of the <i>disorder</i>
Orofacial Examination	This is typical of a “medical checking’ of the structure and function of the oral mechanism.
Types and Frequencies of dysfluencies	The stuttering symptoms are characterised by their specific types and frequencies and by associated symptomatic behaviour. An abnormally high frequency of repetitions, prolongations, interjections and pauses constitutes a fluency disorder- hence a symptomatic analysis of presenting features.
Other parameters of communication Language Voice Hearing	These were assessed to ascertain if there were any <i>deficits</i> in parameters of communication other than fluency. There is no specific mention of his strengths
Recommendation	He must receive treatment to reduce the % disfluency via a fluency-shaping programme to reduce the occurrence of symptoms of stuttering.

APPENDIX B

SAMPLE TREATMENT PLAN AND COMMENTARY

C.2.2. BRIEF TREATMENT PLAN: *FLUENCY DISORDER*

**Speech and Hearing Clinic
Eastern State University
Bedford, California**

James Foxx, a 23-year-old male, was seen on February x, xxxx, for a speech evaluation at the Speech and Hearing Clinic of Eastern State University, Bedford, California. The results of the evaluation indicated a severe fluency disorder with 21% dysfluency rate in conversational speech. His dysfluencies are characterized by repetitions, prolongations, pauses, interjections, and revisions. A fluency treatment program was recommended. With consistent treatment, prognosis for improved fluency was judged good.

A fluency-shaping program was selected for James. The program consists of the following final treatment objective and specific target fluency skills:

Final Treatment Objective: A dysfluency rate that does not exceed 5% in James's home and other nonclinical settings.

TARGET BEHAVIORS

1. **Appropriate management of airflow.** To produce and sustain fluency in conversational speech, James will be taught to inhale and then immediately exhale a slight amount of air before phonation. He also will be taught to sustain smooth flow of air throughout his utterances.
2. **Gentle onset of phonation.** James will be taught to initiate phonation in a soft and easy manner.
3. **Reduced speech rate through syllable prolongation.** James will be taught to prolong vowels to reduce his speech rate and to achieve continuous phonation.
4. **Continuous phonation.** Throughout an utterance, James will be taught to maintain continuous phonation by not pausing between words.
5. **Normal prosody.** Maintenance of normal prosodic features with a dysfluency rate that does not exceed 5%.

TREATMENT PROCEDURES

1. A baseline of dysfluency rates and speech rate in conversational speech will be established before starting the treatment.
2. Treatment will begin at the phrase or short sentence level.
3. The target fluency skills will be taught one at a time, beginning with inhalation and slight exhalation. Gentle onset will then be added, followed by syllable prolongation and other target skills.
4. As James sustains 98% stutter-free speech at each level of response complexity, utterance length will be increased.

- 5. The clinician will give instructions and model target responses consistently in the beginning stages and as often as necessary in subsequent stages of treatment.
- 6. The clinician will verbally reinforce the production of all target behaviors including the resulting fluency.
- 7. The clinician will give corrective feedback for incorrect responses, including dysfluencies; this feedback will be given at the earliest sign of a dysfluency or mismanagement of a target fluency skill.
- 8. When James sustains speech with 2% or less dysfluency, normal prosodic features will be trained by having him increase his speech rate and by using normal intonational patterns.
- 9. As James sustains 98% fluency in conversational speech, maintenance procedures will be implemented. James's wife and a colleague of his will be trained in evoking and reinforcing skills of fluency. James will be taught to self-monitor his fluency skills. The clinician will take James to extraclinical situations to evoke and reinforce his fluency skills. Home speech samples will be used to judge maintenance of fluency.
- 10. Follow-up will be scheduled for 3, 6, and 12 months postdismissal. Booster treatment will be arranged as needed.

Signature: _____

Gloria Marquez, B.A.
Student Clinician

I understand the results of the evaluation and agree to the recommended treatment plan.

Signature: _____

Date: _____

James Foxx

Signature: _____

Henriette Borden Ph.D., CCC-SLP
Speech-Language Pathologist, Supervisor

Table One: Dimensions of a clinical assessment report: issues and commentary

Case report content and structure	Issues and commentary
<p>1. Report format :</p> <p>The categories/headings</p> <p>Background and presenting complaint</p> <p>Assessment information</p> <ul style="list-style-type: none"> -Orofacial examination - Types and frequency of disfluency - Language production and communication 	<p>The report structure and format captures the professional and technologised language of the profession. It is interested in the problem/ disorder and uses a specific discourse/ set of terms to construct the problem : Orofacial, types of disfluency</p>
<p>2. Case History</p>	<p>The history of the stuttering disorder and treatment is captured. This is revealed in the description of the</p> <ul style="list-style-type: none"> - Age of onset - Changes over time - Development of the disorder - Variable nature of the problem - Treatment <p>The social and family history has reference to <i>stuttering</i> only.</p> <p>The social impact of stuttering is mentioned for the <i>individual</i>.</p> <p>The occupational and educational history have reference to stuttering.</p> <p>Hence, the case interview traces the history of the <i>disorder</i></p>
<p>Orofacial Examination</p>	<p>This is typical of a "medical checking" of the structure and function of the oral mechanism.</p>
<p>Types and Frequencies of dysfluencies</p>	<p>The stuttering symptoms are characterised by their specific types and frequencies and by associated symptomatic behaviour. An abnormally high frequency of repetitions, prolongations, interjections and pauses constitutes a fluency disorder- hence a symptomatic analysis of presenting features.</p>
<p>Other parameters of communication</p> <p>Language</p> <p>Voice</p> <p>Hearing</p>	<p>These were assessed to ascertain if there were any <i>deficits</i> in parameters of communication other than fluency. There is no specific mention of his strengths</p>
<p>Recommendation</p>	<p>He must receive treatment to reduce the % disfluency via a fluency-shaping programme to reduce the occurrence of symptoms of stuttering.</p>

I hope this example clearly demonstrates how the clinical examination or assessment seeks to characterise the disorder, and by so doing “essentialises” the individual concerned. Jamie is reconstituted as a client with a fluency disorder or ‘stutterer’. There is singular emphasis on the pathology. I would suggest that the storyteller is, in fact, the professional who conveys the “pathography”.

The treatment plan (Appendix B) reveals the further dominance of the medical model, merged with behaviourist influences.

From : Hegde, 1998

Commentary on a typical treatment plan

Treatment description	Issues and commentary
A fluency treatment programme is recommended	A treatment programme for disorder has a medical orientation
Fluency-shaping programme was selected for Jamie Jamie will be taught to initiate phonation..	The professionals power/ expertise in decisionmaking is apparent
Treatment objective: disfluency rate that does not exceed 5%	Symptomatic relief is promoted
Jamie attends therapy	Individualist emphasis- person has and owns the problem
Treatment procedures	Determined by the therapist in a structured manner
The clinician will give instructions and model target utterances... will reinforce	Behavioural regime is promoted and clinician-controlled
Jamie's wife and colleague will be trained in evoking and reinforcing skills of fluency	Extraclinical support is necessary to support the treatment regime. The support is to monitor fluency skills.
I understand the results of the evaluation and agree to the recommended treatment plan	The client is required to give consent but the report does not reveal his democratic participation in the construction of the clinical regime.

APPENDIX C

PILOT STUDY: REFLECTIONS

Reflecting on methodological choice

I chose the life history approach since it was appealing in the context of my study- i.e. I think it is very useful method to answer my critical questions there are three things which made this attractive

1. the person told his story - I was interested in his subjective view
2. there was a temporal orientation i.e. I could trace the events over time which is important because in this instance I was interested in stuttering which starts in childhood and persists into adulthood - I am interested in how stuttering and people change over time
3. it provided a real context and traces the history of his life and not the pathology- which has been my traditional focus. In doing so it has the potential to be interdisciplinary -life does not have professional boundaries- I also think that to expand my field there must be an extension of the traditional research paradigm - in contrast to the traditional empirical research this makes a conceptual shift to the hermeneutic/critical.

Prior to the interview I had many discussions with colleagues and read extensively about life history- there is a lot available at a theoretical level but not much in the way of practical. I developed a schedule and went into the interview feeling very uncomfortable. I think that the sources of my discomfort stemmed from my lack of familiarity about the method, the fact that the Bongani was Black, male and not well known to me. This is something I will have to really consider when I do the next round - if I don't know the participant how will I manage the situation- developing the relationship etc. In my interactions I have had most interaction with Indian and White people and little with Black people. Also I had never attempted to "uncover a life" although I had worked extensively with adults who stutter and established good relationships.

The first hurdle was to determine if he did stutter. How was I going to do this- stuttering is by nature variable- so you could talk to someone and not know they stutter- some people can be interiorised stutterers i.e. they have determined ways of coping that allow them to provide a fluent "front" but are anxious about their fluency. I decided that it would have to be a consensual understanding i.e. Both participants should have a common agreement -through a trace of history and a description of what communication was like- it would be very difficult for me to go thro an interview-not convinced that the person did stutter.

SO in the first contact when I went to meet with him I explained what I was interested in doing- and asked him to describe his speech- he did- it was typical of stuttering and I could also describe his fluency as being that of stuttering. The initial hurdle for me was to listen past his disfluency. By virtue of my training I listened to all the repetitions etc and would count and classify whilst he spoke. I knew that this would not do and that I had to learn how to listen to the story- it took a while - but I did- focusing on aspects of life not related to stuttering helped me to get interested in the story. After the initial

interview I learned to listen past the disfluency- his disfluency for most parts was mild so it was okay- if severe in other instances- it would become an issue again- but I am more skilled at doing this now but its not easy.

The actual interaction was a concern prior to the interaction- I am generally quiet - perhaps distant- "professional" in my interactions with PWS I am friendly but "professional" similar to my interactions with students. Mershen, who has studied my behaviour, says I draw the lines fairly clearly but easy to get along with - how friendly-casual was I going to be? I finally decided that I could only be myself or else it would be a false presentation. I am so many people. I will just do what feels right and reconsider problems as they arise.

So with this in mind I began the first interview- at the outset he wanted to talk about stuttering only. I didn't really want him to start there - so I redirected the question saying that we would come back to that since I did have an interest in understanding stuttering in his life context- Once it got going there was no looking back- it unfolded easily- we were two people talking EXCEPT- I discovered -it was not a conversation-I was interested in his life experiences of stuttering. The problem was that if I added my life into the mix it started to get confusing- I called Vijay and asked about this - she clarified much of this- it was easier to get his story- and not to confuse it with mine- sometimes I would add in a bit - but only to keep the interaction smooth and natural. I said that I would be saying little- he didn't mind he had so much to tell

The interview went all over the place. I didn't really follow the interview schedule. I suppose I expected it to be in some ways- but I didn't stop it because I knew that when I did the review I would see where the problems were- anyway the story was so interesting that there were many times that he would continue without interruption. Since I was also planning to do a paper at a conference there were particular issues I wanted to know more about- at these points the interaction became more stilted- because it was my interest and not his- some balance is necessary here perhaps? More open-ended questions would have helped

In his case he said that stuttering didn't matter- it was most unusual- because all of my previous professional life told of stuttering differently- but he was different in many ways and so probed about why it wasn't a problem- and got some excellent insights on positive ways to deal with stuttering.

The transcriptions were a difficult time consuming job- but I learned a lot- I had to make some decisions- would I transcribe the disfluency- I didn't because I focused on the story- maybe at another point would however, I heard all the disfluency and realised that I has managed to tune out stuttering- a really nice skill to have if you listen to stuttering on a daily basis!

The gaps are really what I am interested in so that the next part can be more tidy. Vijay read through the transcripts and pointed out the areas I could probe further and where there was too much of "irrelevant" info. From this discussion I went back and reviewed the transcriptions and selected the parts that I would use in the story-and parts where I could probe more- this I used in the new schedule.

In particular:

1. probe issues on stuttering more-especially the think feel and do- I neglected the "feel" bits
2. probe changes over time and changes in handling over time
3. expand parts that are new , interesting- leadership roles
4. probe inculturation process- sounds fancy- but to document how the external and self have interacted- what have been the changes over time - explore identity issues- must read more on this
5. restructure schedule- begin with overview and then the detail- I will do a chronological interview -just easier to handle- but allowing for flexibility.

Thus far a draining process- but I think that the analysis is the biggest challenge- I am determined not to do a reductionist one- especially after collecting all the valuable data- therefore I will construct stories- Polkinghorne - one thing that has made a lot of sense thusfar- I will finalise the interview schedule after I have written the story- so that I can see how much of data and which type I used the most- the most frustrating part is that I have forgotten how to write stories- I am reading- following Vijay's suggestions and this is already helping- I select better words- but still consider this the weakest area- I know how to write an objective report but not a story- Ruth will help with this.

The process is very interesting and despite my very heavy workload I have kept at it- I have sent an abstract to another conference to keep up with the pace- I hope that I will have the story done by then- my next step- and then to finalise the interview schedule- my colleagues at work have all been interested in the story- He has given me permission to share it at any forum using his name- it has really changed my outlook to how I teach students- e.g. using a life history in teaching- asking them for personal reflections in reports and to value subjectivity in the clinical process.

I am learning how to put my thoughts on paper and then to integrate with theory rather than the other way about - it is very difficult to reposition as knowledge constructor than only as knowledge receiver.

I have been very disciplined thusfar and don't want to lose momentum and neither do I want to spend very long on this- it must be done by 2002- if all goes according to plan. Vijay has given me things to do -like- readings- doing an outline of the entire thesis - which really helps to see where all the bits slot in . The one-one one supervision has been most useful- I haven't had this opportunity to discuss this project with Michael at length- I really need to discuss identity issues with him- the group process will complement the individual tutoring very well- for general and specific aspects. I would really like input/ consultant from my own discipline and would like to attend an intensive workshop about data analysis- maybe with Polkinghorne himself - I will try to contact him via the network - I think it would be very worthwhile to have international input.

Date: 15 July 2000

The preparation for the paper for the conference provided a good opportunity to ask more questions about the analysis- not enough time to write the story so I decided to focus on major themes. The planning and preparation was okay- less stressful than I imagined because I had been reading and was gaining a sense of familiarity with the

field. However, it did seem that the issues that were raised i.e. social location of person, the cultural issues were all making me read all over the place- discovered the critical and cultural psychology websites which were most fascinating- gave me a sense of just how interdisciplinary this project was- very scary

I still think that the appreciation of narratives within the speech pathology field is not there and that very few people followed the "real essence"- however. It is gaining popularity in the field as a discovered when I located the journals in the library- stories about stuttering- but not in the way that I had been considering them. Grounded theory designs are really difficult to cope with because it is so unlike the type of research I am used to- very open-ended discovery – you don't really know where you are going.

Writing the story: August 2000: the greatest challenge to date

The thing that I have been avoiding because I realise that I have retained little creative talent ever since I had joined a scientific profession - especially in terms of writing- so I started to read, keep a word and phrase book and pick up books for my children- I discovered the many books that I read as a child and got in touch with the things I really liked- Read the stories that Michael has done- Emmanuel and that Vijay has written- Nozi - seemed less daunting

Analysed text of interview into main areas and themes- the decisions I needed to take was-which voice to write in - I think that since I am writing the story- I will write in my voice and then quote Bongani directly from text- ofcourse he will review it when done. Needed to take on the challenge and start somewhere- Gergen's info on the construction of the narrative was most useful- the story must have an endpoint and must be constructed around this with plots and theme etc.

I am still not sure if I know what plots and themes are specifically- I know them intuitively in knowing how to write my story

September 2000

I am preparing for the second interview- I had been enjoying Bongani story as a very different one-however I am well aware that I still need to get stories of people for whom stuttering is a problem since these are likely to be the people who I will meet -

I think from my discussion with Mershen I will need to position myself as a learner in the research process. As I read both within the field and outside the field I realise that each time I read and learn the more I want to probe certain areas and the more I want to revise the schedule- it will not be possible to know what I will see along the way because it is really a journey in to the unknown- so I think that a sequential theoretical sampling will be useful

At the same time I am acutely aware that whilst I continue to revise the process will always be incomplete. Spoke to Vijay -who has always asked about focus and what questions I think that I must be more specific in what I want to explore- do a "map" of all the issues that I need to draw in the context of stuttering and life experiences I feel that it is really important to go back to the research in the field to consider what issues they are looking at- e.g. issues of tone, self-assertiveness have emerged - the field also

seems set to explore new methodologies- I would really like to write the research paper after the Birmingham paper

I think that in terms of process I would like to do a case by case analysis and drawing and building on each -each is likely to illuminate a different aspect and may be this is one way of demonstrating the issues underlying the experiences I really want to speak back to the field especially about the potential for developing developing narrative therapy (later!!).reading - just discovered a PHd project in USC by Sue 'O Brien -must get a copy seems like the kinds of issues I really need to read more about

The Birmingham paper will allow me to get into issues of analysis. Illness stories provides an excellent and sound basis for understanding illness stories and how the theory underlying the narratives help to understanding the issues - good theoretical frame also need to link this with issues of the self- piece all of these together as the analysis using Habermas as the overarching frame?

The pilot phase was most useful I just wish that I had received more detailed feedback on the story it self from the participant. Maybe not everyone is interested in this. I will invite participation. That the best I can do. I could send it to another person just to review the plausibility of the story should the participant not be available.

I feel a bit more comfortable but now I have more questions than answers-as usual.

BONGANI'S STORY

Introductory Commentary

At my initial meeting with Bongani I invited him to tell his story in the context of the broad purpose of my research. He began enthusiastically, telling me about his early life about stuttering and communication. As he told of his life and experiences it soon became apparent that stuttering was “not an issue” for him. Throughout the interview I listened intently and tried to understand this fascinating story. As a speech pathologist I had interacted with many PWS and their stories have been constructed around themes of illness and suffering. This one was different...

THE BEGINNINGS

Bongani Khubeka was born in the African township of Clermont, Kwa-Zulu Natal in 1964. It was the apartheid era in South Africa. With oppressive racial segregation policies firmly in place the Khubeka family established their homestead in the Black township of Clermont. Born into a Zulu community, Bongani had little exposure to the White, Indian and Coloured communities in South Africa. Through a child's eyes they were strangers-spoke different languages, went to separate schools in different education departments, lived in different areas. A typical South African way of life.

The early days Nquavini

As a young child, the fourth sibling, he shared his childhood with six brothers and four sisters, parents, maternal and paternal grandparents. Unlike any of his siblings he was very volatile, sensitive and threw tantrums - a very different child. When angered, he would fly into an uncontrollable rage. The behaviour that followed caused everyone to take cover. He would release their vicious dogs, throw any objects - chairs, eggs in his path. His mother would frantically clear out all “dangerous weapons” in the household. His aggressive behaviour earned him the title of Nquavini after an urban legend set in Richmond, Natal Midlands. The character, Nquavini, was notorious for his temper, would, in a blind rage, murder people including family members. Bongani was rebellious, aggressive and “a bully” at school and at home. On reflection, he suggested that his anger and frustration was a response to stuttering to “not being able to talk”. Being physical was a quicker way to communicate. It is the first time ever that he has linked his violent behaviour and stuttering in childhood, and has offered such interpretation. He is convinced that they are related and reinforces this notion on many occasions.

His parents did not draw any attention to his stuttering. He explained that among the Black community at that time stuttering was not viewed as a problem because it was understood as something “one would grow out of”. In Zulu, stuttering is called “amalimi” which means the repetitions of words or sounds. People would attempt to “manage” stuttering in different ways. Whilst some would consult the traditional healer, others would perform rituals to communicate with ancestors. Some would do nothing. There was little exposure to formal literature in the community regarding stuttering and its management. The cultural norm did not accord any significant status to stuttering and therefore it was not an issue. However, beliefs and traditions change over time and the situation may be different today, especially in the classroom. He talks about this later.

Bongani’s family has a strong Christian influence in their upbringing. In their family tree there are priests and pastors on the maternal and paternal sides. Therefore, none of the traditional African rituals were performed in response to his stuttering. He has never had a conversation with his parents about stuttering and contemplates doing that now. He would really like to fathom whether they thought of his speech as a problem. He is almost certain that despite them having observed his violent behaviour and stuttering as separate events it is highly unlikely that they saw any connection between the two.

At primary school he was a strong academic achiever and excelled in all subjects. He read furiously- anything he could get his hands on but remained a constant challenge to teachers. He was a daring and fearless. He once played truant for six months whilst at primary school. After dropping off his younger sister at school, he would proceed to his school and spend the time in the ablution block and pick fights with other children especially those in higher grades. The saga ended after his parents discovered that he forged a half-year report and had inadvertently included subjects that were not part of the curriculum. After severe disciplinary action he returned to school and continued with his rebellion. He was fiercely protective of his family and friends at school, and in the neighbourhood and soon became the well-known and much feared local bully.

During this time he was aware of his stuttering and once again suggests that his volatile behaviour was linked to the fact that he could not communicate effectively. Other children did stutter and teasing was a reality. However, the experience was different for him because, having established himself as a bully, schoolmates were scared to tease him fearing the consequences. He did not receive any help formally but recalls that his mother did help him to read at a reduced paced - possibly a strategy to manage stuttering. His disfluency was severe at the time. He would get “stuck” and find it difficult to end the block. Amid immense frustration he reacted with physical aggression.

TURBULENT TIMES

Secondary school days

Bongani grew up in a community that was at the forefront of the political struggle for a nonracial democracy. His family had always been politically conscious and so it was early

in his life that he was educated and exposed to the harsh social injustices that prevailed. He was twelve years old in 1976- a time of greater political upheaval in South Africa. The participation in political youth programmes fuelled his ambition to be a social/political activist. Youth, anger, and idealism combined with political fervour produced a fiery combustion. His activities and rebellion could not be contained within the regular school system and as a security/ precautionary measure he was sent to Ohlanga a boarding “rehabilitation” School. He is quick to point out “ I don’t really like the term rehabilitation” “Rehabilitation” has a negative connotation of something wrong that one must put right. However, in this context the “rehabilitation school ” was for those who were politically mature and who rebelled against the system. He points out the contradiction - if you were defiant - then you went to rehabilitation school- however, defiance was not something bad -given the context. The institution was an academic institution but encouraged for active political engagement. It served to accelerate his personal political maturation process.

He recalls his cherished memories as though they happened yesterday. The principal would welcome you with open hands. Bongani was fortunate to have a bed in the senior block and benefited from the incisive political intellect of senior students. His own knowledge and understanding of the extremely complex roles and relationships of the various organisations like the ANC, IFP AZAPO, PAC were honed in this environment. He produced a long arc of definitive evidence as he traced in detail the events that led to the political uprising in the country.

The school programme was unique. A full academic programme was offered of which there was a political education component. The latter included political debates, events, discussion forums. Bongani participated in all of these. He spoke animatedly and with great nostalgia about the times at Ohlanga. Through this I gained perspective of his sense the sense of commitment and intensity of belief in the political struggle. It is also apparent that these activities were character building and cast the foundation for the development of leadership skills.

Life changed dramatically after three years at Ohlanga. Bongani was moved to another boarding school in Bulwer- a Missionary School. The decision was his fathers. He was concerned that because Bongani had become “too involved” in politics and that such immersion in political activity posed a great security risk. Many young South African activists at the time lost their lives at the hands of the State. As the plot deepens, I am aware that we have not talked about stuttering to any significant extent. However, it does appear to me that the issues under discussion were far more momentous and consequential - so we take up the discussion later.

Bongani displayed his anger and frustration shortly upon arriving at the new school in Bulwer. He had his first fight within two hours. He remained there until he matriculated but the political will was strong. Despite the long distance, he traveled regularly to Durban to continue with his activities. Upon matriculation it became necessary to make

critical decisions about his future. His views and those of his fathers were discordant. His father had the final say.

Of family and education...

For Bongani in particular, the choice of teaching as a career was considered important by his parents because of his interest in community and political matters, coupled by a need for discipline in with his highly volatile personality. His father, acutely aware of his political inclination and ambition and determination persuaded him to pursue teaching as a career instead of taking up a scholarship to do Political Science in London. His father was also concerned that he would leave the country illegally since his passport had been suspended. So Bongani's father took it upon himself to register Bongani him at a teaching college. Upon reflection, Bongani agrees that this was a good decision. It appears that stuttering did not feature as a consideration for choice of career by himself or his family. He does not elaborate. As he told his story I developed a greater appreciation of this.

Bongani is not the only teacher in the family. He provided a very proud account of his family and their history and achievement despite an oppressive apartheid policies. His mother and father, who are living, are teachers. Nine of the ten siblings are professional people: lawyer, engineer, neurosurgeon, dentist, school principal, community development officer: eight began their careers as teachers. Drawing on their own teaching backgrounds, his parents decided that it would be a good starting point for their children because it "nurtures you about how to be with the public" and provided good discipline. There is the lastborn who is "chaos" and has not pursued a career.

The family is described as having "high social values". We explore this and it becomes apparent that there is emphasis on leadership, respect and education, on the family as a strong supportive network. The family has been involved in the business sector for as long as Bongani can remember. They have been labeled by some as the "bourgeois" which does not bother Bongani although he is aware that in some instances it can become a sensitive topic. The community at large is diverse in many respects like economic status, education levels, religious practice. The Zulu language and tradition forms a common bond across households and the community.

Bongani's rearing was influenced strongly by values underpinning Christian and Zulu tradition. For Bongani "African" means to follow the values and customs of Africa people, to speak the language and to engage in traditional rituals such as the slaughtering of cows and goats to communicate with the ancestors. He does not consider himself a traditionalist but does respect the rituals that may need to be performed- a pragmatist.

The Nucleus of Eight

Bongani is adamant that the "Nucleus of Eight" cannot be left out of any story about his life. The nucleus refers to the group of eight childhood friends who, during political

struggle, formed a nucleus. During the ANC underground operations the Nucleus of Eight formed a cell who organised and executed underground activities with military precision. Bongani was the leader of the cell- the Commissar. Unlike the other cells which were formed by comrades who didn't know each other well for security reasons, this cell was formed by comrades who were all from Clermont and who grew up as childhood friends. They led double life. During the day they were community citizens by day and political activists by night. Bongani was the natural leader. His candor, experience and his science background proved to be useful especially when they manufactured petrol bombs with a great deal of sophistication. The cell operated with a military style of discipline and had a collective determinism. They were not allowed to reveal their identities or to reveal the names of other political activists even when tortured by police. They succeeded with this. Although he was aware of his stuttering in the context of the nucleus it would never become an issue. He was had a position of seniority, was a military disciplinarian no one would "make fun of my disability"

By day the nucleus are friends. His ruminations here move back and forth in time because they have a history and still meet with each other on a regular basis. There is little they do now without consulting each other. During the struggle they would support each other with personal matters and worked as a collective on any aspect of community life. The strength of their friendship and their commitment is illuminated when he tells of their experiences with the police. The police used a "divide and rule" tactics to gain access to information. Bheki, who was a part of the cell was imprisoned and tortured for six months but did not reveal any information. They shared many trials and tribulations- stuttering by comparison was a lesser issue. From Bongani's perspective stuttering did not appear to be elevated to the status of any importance.

Political activities continue

The turning point

The combined influences of the activism in the community and teacher education training culminated in a very rapid maturation process. During this time the violence and aggression simmered. This coincided with many of the leadership positions that Bongani held and was required to be in control. The state of "being in control" is described as being "empowered" as having "knowledge and information" In a leadership position he was required to attend to disciplinary issues. He had to coordinate the street committees according to organisational policy and to ensure that they operated in a responsible way. The 'People's Court') people's justice - or what actually became known as the "Kangaroo Court" *** The purpose of the exercise was to shift the control away from the South African Police and to deny access to information to the "enemy". The situation in the township was at times hostile and people would "cry blood". Great discipline and restraint was necessary on Bongani's part to educate people that the structures were not meant to serve as killing machines but rather as empowering machines. This process helped him to become focused and disciplined and "in control".

The underground activities continued in Clermont and reached a pinnacle in the late 1980's. Bongani had qualified as a teacher. A penalty for political activity was that he was blacklisted and could not get a job as a teacher in the public sector upon qualification. The involvement in the formation of teacher unions were a perceived threat to the stability of the system. Undeterred, he continued with the political activity spurred on by the fact that ANC was gaining momentum and there was talk of the release of Nelson Mandela. The workshops and political awareness campaigns had to be planned in a strategic manner such that the Special Branch of the South African Police would not be able to disrupt their activities. Bongani was in the forefront of these activities. Under the guise of running an Art workshop or a talent contest, people of the community would receive political instruction. Although Bongani was never arrested he was repeatedly questioned by the police. However, his activities did not go unnoticed. His passport was suspended after it was discovered that he ran covert political activities using a minibus which he registered as a taxi. Bongani made numerous trips to Lusaka, Zimbabwe and Lesotho. In the course of these trysts he gained political wisdom and life skills that enriched his understanding of the world.

There are many times during the interview when I question or wonder about the stuttering. Sometimes this occurred because I was aware of the actual disfluencies during the interview. Interestingly, at other times I was unaware of stuttering as I focused on the many aspects of his life that he chose to foreground. Bongani continued to dismiss stuttering or made only fleeting reference to it reinforcing that it was not important or "not an issue". I get the feeling that he has to paint a greater landscape before we can get to details. I invited him to tell his story and so I listened. As I listened to the story it was clear that his was a life of great experience- stuttering was part of it- but not all of it- I still wanted to know more.

The educator...

Bongani's involvement with politics extended into the teacher training phase of his life. He was blacklisted and upon qualification he was not allowed access into the government run Education Department. He began a seven-year teaching career at Pambile School, a private school in Durban. By this stage he was "more focused" and also knew how to use the education system to political benefit. He taught politics in an integrated way- with Science, Maths and Biology. But as he tells the story about Pambile, it is clear that it was an ideal teaching location for someone with his background. Pambile was established to educate those activists who were expelled from school because of their activism. The teachers at Pambile carried the responsibility to help them complete their matric. There was a great sense of obligation to educate students about their roles as future leaders. It had to become clear that politics was "not about attacking and fighting" and that the struggle had to be sustained in a positive way. Education had to address life issues.

Although Bongani stutters, he has always been confident, despite the reliance on oral communication in the teaching profession. His conversation drifts into his class room experiences of children who stutter. His own experiences with stuttering sensitised him

to children who stuttered. As a result, he has assisted children who stutter during his teaching career. In his commentary he raises many issues. He says that although parents may not have accorded any importance to stuttering, teachers are likely to, by virtue of their awareness during their training. All learners are individuals and teachers are obliged to help them whatever their difficulties- stuttering may be one of them. The education system unfortunately is designed for the “average” pupil which does not exist. The teacher must take an individual approach to understanding each child and not to see the child as a “shortcoming” or having deficits. The teaching curriculum should equip teachers with an indepth understanding of child psychology.

The extent to which child who stutters may be viewed as a “problem” depends on how the teacher manages the situation. If the teacher is positive the he can assist the child with techniques that help. In the classroom situation he has assisted pupils with fluency skills. It is also very likely that the child who stutters may not be considered as having a major problem compared to those who have problems with visions and hearing that would impede the learning process. He suggests that the child who stutters may compensate by writing well- using written communication.

However, the class room situation is really aggravated when teachers don’t understand and know how to treat stuttering. They ridicule the child, start to speak when he is speaking or do not give him opportunity to speak at all. The teacher should rather help by educating himself, and the children in the class and providing the child with useful skills such as rate reduction and breath stream management to assist the child. There have been no speech therapists or any kind of professional help in Clermont. The school would be a good place to begin an education and awareness exercise. The teacher spends the most time with the child and can assist.

Of leadership...

I am interested in why he has taken on leadership positions and the qualities he has to fulfil those roles. Leadership was strongly valued in the family. To be a good leader one had to be a good listener, a strategist, disciplinarian, strong, tough and good at communication. He developed and refined these skills over time. It also appeared that the types of roles he has played within the classroom, as community leader and as an activist, development officer, father and husband has allowed him to explore a range of strategies including those related to communication to decide which works best in a given context.

THE FRUIT OF LABOUR

1994: Bongani turned thirty and the ANC won the Clermont election with landslide victory. The hard work had paid off. Victory was celebrated. The country had made history without the anticipated bloodbath. Bongani was obviously proud to have been instrumental in the process. I expected that he would have then occupied higher profile position political position given his determination and leadership qualities. However, not

everything runs smoothly especially in politics and Clermont was no exception. The interests of the collective ANC were placed above all else, and so personal ambitions were not promoted. However, Bongani was well aware that the real work had not yet begun.

The community social worker

Bongani is now officially a community development facilitator officer with the Inner West City Council and is based in Clermont. At this point in his life this image is strongly promoted in his multifaceted identity. After South Africa's first democratic election in 1994 it was natural transition for him to the role of "social worker" in the community. His commitment to Clermont is once again accentuated. Clermont is a special place. He has all of his roots in Clermont and feels a strong sense of obligation to "give back" to the community. He describes Clermont as vibrant, densely populated with shacks, shebeens and tuckshops, congested, and a place where life begins after six. It is here that he has formed all of his significant relationships, received education both formal and informal and developed a sense of community living. He wants to give back to the community that nurtured him.

His role of Community Facilitation Officer had began long before he assumed the formal position within the Inner West City Council. During this time he had been leader of the any forums of Clermont which have been largely responsible for develop initiatives. The intimate knowledge of the community and his passion about development is demonstrated when he tells of his workshedule. In this job he is an interpreter between the worlds of social activism, policy and policymaking. The days begin very early and work continues until late at night. He is seldom home before nine in the evening because this is when the community is available. He only takes compulsory time off on a Sunday morning to attend Church- which he tells me about at another time.

Reflecting on his role in the community, he explains that his style of interaction has changed. Whereas in the days of the struggle he was the leader with a mandate to speak for the community and to direct the community, now his role is one of consultation. This means that he has to listen to what community members say and to work together with them- a negotiation that can prove to be both tiring and frustrating. However, once again he tells of the skills necessary to conduct this job. A trilogy of skills is described. Being a good listener is more critical than it ever was previously. It is also of prime importance to be a good strategist- this has carried over from the cell operations. He spends part of his time putting plans together- working out strategies. A third skill is the ability to network.

The philosophical thrust/ ideology that guides his living is pervasive. I get this sense when he talks about the projects he is involved with and the way in which he facilitates them. Among the many projects he tells of one in which there is an outbreak of cholera because the stream running through the township has been contaminated. A Primary Health Care orientation to solving the problem has been used - both in principle and strategy. Issues of health promotion and prevention sustainability of initiatives are

discussed with the community. The strategies depend on intersectoral collaboration to address complex range of issues including skill development, fundraising, immunisation, environmental health, engineering, education. His task is to facilitate such projects which don't go on smoothly and conflict management is part of the job.

The greatest challenge is to shift the paradigm that guides present day political activism. The days of reactive approaches are over and it has become necessary to approach the community development in a proactive manner. However, the will to do this has not been sustained by the community at large. The fall in numbers in the membership of political organisations and the lack of urgency and responsiveness demonstrate this. This makes the leadership task very strenuous and demanding. He reemphasises that turnaround in leadership style means that he is obliged to consult with the community on issues where their may signal dissonance. In a carefully crafted negotiation process he must not promote party interests since the community approach is an inclusive one. The process challenges his patience and tolerance- at times his plans have been completely shelved in favour of the community's. He may exit the process with a migraine. Despite this, he continues. There have been successes with community programmes. The life skills programme, AIDS awareness and economics upliftment initiatives are signs that the community will help themselves. Transformation process is a very difficult one and his job entails dealing with this on a daily basis.

On a daily basis, Bongani interacts with school-children, pensioners, clerks, project managers, councilors, community members, representatives of the church, visitors to the community, academics, trainers. It is in these contexts he continually adds new skills to his repertoire. One that has become important is "not to succumb to pressure". He has the responsibility to ensure that projects are sustainable and therefore cannot accept decisions without scrutiny but is careful to engage in conversations with great diplomacy. He draws on all of these resources to navigate the terrain. He speaks in Zulu, switches to English if necessary, observes that rules of the communicative interaction, preplans responses. If he senses that he is becoming emotional, defensive and out of control, he will ask a question "at a tangent" until he can regain composure. Taking a deep breath and a moment to relax are useful to combat microaggressions. Attempts to control fluency are successful but are used selectively. Monitoring fluency can be tiresome and draining if it has to be continued over prolonged periods.

He feels empowered in any situation in which he has knowledge. In any given situation he would appropriate knowledge to his advantage. The political grounding has taught him to be a strategist. He would therefore navigate every situation according to a strategic plan. He would conjure up a plan about how to run a meeting, the information to present, the types of questions to anticipate, how to deal with people and responses that are problematic. He would select the language that would best achieve the communicative end, switch languages according to the purposes and audiences, learn the rules of the communicative partners.

In the community, stuttering has never been an issue of primary concern. Since it has been accepted as part of who he is and has not compromised his ability to communicate and forms bonds especially within the community, he does not consciously attempt to maintain fluency. In the community the issues of crime, housing and major illnesses like TB and AIDS widespread and have been prioritised. This did not mean that the people who stutter did have not been affected by it. In a typical classroom for example the teacher would be more concerned about the learning problems and problems of hearing and vision than of speech fluency. There has never been any speech therapist in the community and the community at large perhaps do not share the Western awareness about stuttering and interventions. However, the community is a heterogeneous mix of people who, despite their similarities are unlikely to have uniform/stereotypic views on stuttering.

The best of all worlds...

Bongani enjoys talking. I discovered this as his stories unfolded easily. Communication is the central mechanism whereby one develops relationships. Language is part of culture and culture is about things that allow you to bond- your values and beliefs. The bonding with the community began in very early life. During his early years he mainly communicated in Zulu with minimal to English and was immersed within an African way of living. However, the exposures he had through education, reading and political activities influenced him in a variety of ways. “I grab the best of all worlds- whatever works for me” is his philosophy. He has equal proficiency in English and Zulu and stutters in both language but has had little impact on his ability to form relationships and bonds.

Turning disadvantage into advantage...

Bongani tells about his interaction with people of other languages and race and cultural groups. Race and culture are thorny issues, yet such interactions are encountered on a daily basis in every communicative context. At this juncture in the history of South Africa, it is of particular significance. I get the impression that he has dealt with these issues, like the many other issues, ideologically. This has served to mold his communicative poise. He draws on his multicultural encounters during the days of political activism and applies this learning in his current context. One could view Black as being disadvantage one considering the country’s political history. However, early in life he developed a resilience and turned “disadvantage” into advantage. Education is one powerful strategy to turn disadvantage into advantage- you cannot change the fact that you are Black. He also learnt that when one is an activist then colour does not count. “You see all people as resources”. His thinking has been guided by a human rights orientation. The political struggle was not just about race and colour it is about fighting the injustices of oppression in any form -it is about human rights. I cannot resist asking whether stuttering has been a disadvantage or disability. Would it have been better if he didn’t stutter? He answers to the contrary- stuttering has taught me skills about how to

communicate more effectively- “I can delay a response... while I am trying to think...I have made it an advantage”

“In any communication one creates barriers if one places race as an obstacle. You will then have two barriers to overcome- the first of colour and the second to find a way of interacting” bridging the cultural divide. He once again draws on his engagement with people of multinational backgrounds allowing him to be educated about various cultures and practice. When getting to understand people one could learn about them by being with them and learning about the various aspects of their lives, especially the communication rules which guide his interpersonal interaction.

The daily context requires communication with people of diverse backgrounds. Bongani uses the accumulated skills that he has on understanding human behaviour to his advantage. He learns the rules of the game- the cultural norms for communication and uses this to enhance the interaction. When to speak, when not to speak, when to be silent when to maintain and not maintain eyecontact, turntaking rules... When necessary he would control fluency to the extent that it would not be possible to tell that he stutters. This occurs mainly in the work context in formal meetings.

The days ease off with a meeting with friends. Here he does not make any attempt to control disfluencies. They know about how he speaks and he does not bother with it. Their conversations are a mix of English, Zulu and Tsotsi-taal, a casual / slang that helps him to maintain the bonds of friendship. He does not say so but it is apparent that he is well-liked and very popular. His witty humor and jovial disposition during our conversations are certainly marked aspects of his character.

I'm only human...

He tells me about a stressful communicative interaction. The scenario of a typical meeting would unfold with the usual procedure. He comments that being familiar with procedures are important. In such meeting he is a participant and not in charge. This type of meeting involving councilors and other in authority could be stressful. “ I react like a normal person- I get very stressed sometimes” He describes the councilors as being typical authority figures and a situation in which he is acutely aware of power imbalances. Here, he would go well-prepared with the necessary information, and respond according to meeting protocol. If he discovers that he is losing control then he would sway the discussion in another direction until he has gained composure and will return to the topic. However, meetings are part of every day activity and become easier as there is increased interaction with various participants. Bongani's speech control techniques include reducing speech rate and breath stream management. He has mastered this technique to a point where his communication partners would not know that he stutters. However, he has a strong internal constitution that supports his external confidence. He would use these techniques primarily in business meetings or if he felt the need to be fluent in any given context. It is sometimes excruciating to control external expression and maintain an unruffled exterior while trying to suppress angry emotion. On some occasions he would

feel extremely stressed to a point where he could “burst” and would end up with a migraine. A strong cup of coffee provides some comfort after such incidences.

STABILITY

In recounting a very busy lifestyle it seems that there is also a sense of stability and peace. The turbulent political times have passed and a new set of issues have become important. “I am more of a family man have become actively involved with Church”. Places these issues in context. In the early days of rebellion he also rebelled against the Church- not in ideology but in the practice of rituals. The Church had to become actively involved in practical matters in the community. He demonstrated his rebellion by only singing part of the religious songs at school for as long as teachers looked in his direction and would stop as soon as they turned away. He would stand outside of the church on the occasion of family funerals. He read the Bible from cover-to-cover and argued his rebellion.

In 1994, there were significant changes at many levels. South Africa has been victorious. A new democracy signaled a prosperous future. The Universal Church was established in South Africa. Bongani’s attended a service held in Durban. It was “ very very open- it addressed day to day issues -they don’t talk of heaven only. He decided to reestablish his links with the church. Encouraged by his sister who had given up her dental career to become a full-time member of Church, he is now an active participant. He is also involved in projects run by the Church. They have secured an orphanage in KwaMashu and are involved with issues that are real. It is here that he gains spiritual perspective- a time to think and reflect. “Its good to talk about heaven-but heaven is here” - another ideology that is consonant with his practice.

The family man

Bongani’s life has always included his family. However, in referring to life as a family man he tells of his immediate family. He met his wife around the same time that he returned to the Church. It was an added bonus that she he was also a member of the same church- but it was not this that brought them together. They only discovered this six months into the relationship when they accidentally met at a Church rally. She had moved into the Clermont with her family and it was in this context that he got to know her. She is quiet, simple, friendly and “down-to-earth and hates the limelight”. In this relationship she takes many of the decisions as the homemaker and mother. Unlike him, she was not exposed to a public life. Bongani maintains a peaceful relationship with his wife and family although the remnants of his fiery personality do surface occasionally. He has modeled their relationship in part on his parents. There has “never been a quarrel” His mother made decisions about home and business.

I inquire about the issue of stuttering in the relationship. Whilst it had been acknowledged that he stutters, once again he explains that it is not of significance. He explained to his wife that I had been conducting this interview and she was surprised with the interest in that aspect of his life. He went on to explain that no one else in the family stutters and

describes his children as “normal”. He had always been able to establish relationships easily and stuttering prevent him from establishing such relationships. His account of previous relationships demonstrates this convincingly.

His relationship with his children show up the generational similarities and differences. There is greater freedom with decision making and his children have not been encouraged to be politically motivated. Times have changed and their experiences in a post-apartheid South Africa are very different to his own. The issues have changed and they will be allowed to decide the paths they will follow. However, some values are upheld steadfastly. Leadership, education, family-bonding and respect are strong core values that are untiring promoted.

BONGANI AND STUTTERING

Final words...

Personal theory of stuttering

Everyone has their theory of stuttering. Bongani describes stuttering as the problems of fluency with speech- the disruptions taking the form of repetitions. He is something that he was born with that despite changes, has been with him since childhood. Like with all people who stutter, there is variability in severity and there are situations when he can control his fluency to the extent that it would be hardly noticeable. The problem of stuttering is related to the brain and not the mouth. There is a shortcircuit -like that of a seizure -as if there is miscommunication in the brain. Perhaps it may not even be linked to the speech mechanism per se - it may be an outcome of another miscommunication in the brain.

I had been listening intently to the story mesmerised by the experiences that at some points resonated with my own experiences and at other times completely differently from my own reality. I cannot help but ask the question “ Who is Bongani” and what of stuttering. It had not featured as a significant part of his story. Ofcourse, as part of my own inquiry what I also wanted to know was whether stuttering featured in the formation of his identity. It is difficult to fathom- it is a real lived experience but certainly not foregrounded. When he meets people- new people he does not mention that he stutters- “it is not strategic- the way that I see it is to overlook it- not even to make it an issue- I realise that once you start to make people aware of the problem you may get unwarranted sympathy- and I hate that.” He is a confident person and is of the belief that if your shortcoming is flaunted then it will dampen confidence and force one to control which may not be necessary. Subconsciously, one could really increase the frequency of the occurrence of stuttering in such an instance.

In such situations he would not control disfluencies and would “ just burst” until he had his say and was “through with you”. When pushed to the limit he could still resort to “being physical- like I am declaring war” especially if he is bent on completing the

conversation in the shortest possible time as a way manage stuttering. This fortunately happens rarely but those who know Bongani well, especially his history are well aware of his fiery disposition that could surface from a seemingly calm exterior. When in a situation where he receives negative feedback about his communication he has learnt to develop a strong resilience. He describes his retaliation “ I ignore it - once I have my set my path - whatever the reaction that comes- its like closing my ears- I am good at that”

Fortunately he has had to deal with negative listeners infrequently because he has matured is able to control his temper better and has better control over his fluency.

We were reviewing a story written by PWS from Italy. He identified with many of the issues raised in the story. The humiliation suffered by children who stutter, the teasing, the descriptions of speech behaviour. However, once again he points out that whilst there were points of convergence there are also points of divergence in relation to his own experience. The divergence relates to the issue of “early scars that were difficult to heal”. This was not engraved in his personal experience. Also, the reaction from listeners was generally positive only peppered with some negative reaction. The story refers to the deck of cards - he analyses this and says that he started out with a bad deck but played well and turned the game around. “It really is about how you play the game. I can face any challenge- turn disadvantage into advantage”.

On the process...

The process has been close and personal “I have unpacked myself” These were his closing comments.

Harsha : 25 August 2000 : First draft story : pilot phase

APPENDIX D

GUIDELINES FOR PARTICIPANTS FOR THE INITIAL INTERVIEW

1. The research is interested in life experiences of PWS. I explained my decision to invite them to participation in relation to the selection criteria.
2. The study was initiated because I felt as a practitioner that I did not understand the experiences of PWS. Sufficiently. I was the researcher in the study. The methodology involved talking at length with PWS on an individual basis.
3. Each participant would be expected to share their stories on an individual basis. Our conversations would be tape-recorded. Only those directly involved in the project, the people assisting with transcriptions and supervisors would have access to the tapes. Their confidentiality was guaranteed. I would not disclose the identities during the research process.
4. The interviews were conversational. I was not interested in analysing their stutter as is frequently done in the clinical situation. I wanted to hear their stories. I would wait for them to complete their stories without interruption when they did stutter. They should provide me with any guidelines they thought useful to enhance our communication. Should they have any concerns, these should be raised.
5. The research process was interview-based. The interviews would be scheduled weekly for approximately three sessions. The times and dates were at their convenience.
6. An overview of the process was explained viz. The first step was to produce the data during the interviews. In the next phase they would be invited to participate in the story review process and to provide analytical commentary.
7. The interview would be open-ended and they could select any events or issues they thought important to share their experiences of stuttering in their life worlds. I have structured the interview chronologically but they were free to move back and forth as they wished.
8. They were free to discontinue the process, should they wish.
9. They were free to ask any questions at any time
10. I required biographical and contact details.

APPENDIX E

SAMPLE COPY OF CONSENT FORM

CONSENT AND PARTICIPATION IN RESEARCH PROCESS

Project: Life Histories of People Who Stutter
Researcher: Harsha Kathard
University of Durban-Westville
Educational Studies
Doctor of Education

I, _____ hereby confirm my voluntarily participation in the following phases of the above-mentioned research project.

- i. Interview process
- ii. Story review process
- iii. Story review feedback process

Name:
Signature:
Date:

APPENDIX F

INTERVIEW SCHEDULES

Interview Schedule One

Purpose: To establish research relationship, obtain/confirm, general biographical data and gain a broad overview of experience of stuttering during their life courses.

Biographical data

Name:

D.O.B:

Age:

Language:

Race:

Current residence:

Occupational history:

Description of stuttering:

Guiding questions

1. *Tell me about what is significant about your life now? Any important events or issues you would like to discuss e.g. I have just graduated from college, my father died recently, I have changed jobs*

2. *As this is a life history tell me about some of the significant happenings in your early childhood Tell me about the events in your childhood.*

3. *How did you experience stuttering in childhood. Tell me about significant events and people Place stuttering in context of these happenings. What were your earliest memories of stuttering.*

4. *Tell me about some of the significant happenings in your country, community, over your life course and how these have influenced your experiences of in general and of stuttering in particular. (Explore as they became available in the story).*

Childhood: Tell me about experiences in your home context: Explore:

Description of Family: Grandparents, parents, siblings, children, other significant people

Characteristics (personal, emotional, communicative) of family members especially those who had significant impact on the individuals life

Influence of family on individual's life

What were you like as a child? Activities, interests, dreams

How were these events and issues related to your experience of stuttering.

Describe your communication exchanges and significant relationships. How did these shape your experience of stuttering
What did you do to manage or negotiate stuttering
What did others do? Why?
What was your understanding of stuttering?
Were there family members or others who stuttered. What was your experience with them?
What were the languages you were exposed to and why? How did this influence communication and experiences of stuttering.

Educational history

Which were the most significant events in your school life? How did these experience influence experience of stuttering?
Schools attended, performance at school, preschool, primary, secondary, post secondary.
What were classroom experiences like? What was your relationship with teachers. How did they respond to you? What happened that was most significant? What activities did you participate in? What did you enjoy and what didn't you enjoy. Who did you spend time with?
How did you progress academically?
What were your most significant achievements?

Relationships: During childhood

Which have been significant/ Friends/relationships
How were relationships been established? Long term/short-term
Closeness/intimacy of relationships
Experiences in various relationships
Communication in relationships
Place stuttering experiences in the context of these relationships.

Adolescent years

Which were the most significant events
Who influenced you and in what ways
What were the nature of peer groups, influences, pressures
What did you do as leisure activities
What was the experience of stuttering like? How had it changes since your early years.
How would you describe yourself during this time?
What changes occurred with stuttering and how did you cope?
How did others cope?
What was your understanding of stuttering?
What were your ambitions or goals?
What were your most significant achievements?

Adulthood

Tell me about what happened after school/adolescent years

When did you consider yourself an adult?
Which were your most significant experiences through adulthood?
What did you do upon leaving school and why?
How did stuttering come into life decisions?
Who were the people most significant in home, educational, work and social contexts and how did they influence your experiences-in general-and of stuttering?
How did you experience stuttering in varied contexts?
What was the nature of work and work environment?
How did you experience communication in the workplace?
What were your most significant achievements?
How did you negotiate stuttering. What had changed? Why?

Interview Schedule Two

Purpose: Having gained a broad understanding of how stuttering unfolded during the life this interview was structured to gain an indepth understanding of the experience of stuttering using episodes and issues drawn from the initial interview.

Guiding question: Having lived with stuttering and shared how the experienced stuttering over different times in your life, I want to explore some of those times in greater depth. Using some of the issues and incidents we talked about in the previous session can we begin with a particular instance?

These incidents and changes over time were explored in greater detail wrt to issues which were pertinent to the experience.

What is your understanding of stuttering at that time?
How did you develop this understanding?
How did this understanding change over time? Why?
How does the stuttering event unfold? How do you feel when you speak and before during and after you stutter/ conversation?
What do you think about when you stutter?
How does the experience vary and change? How would you explain this?
How do you think the listener deals with stuttering? Why
What are the positive /negative responses that you have had over time and how did you deal with that
How much life energy does stuttering occupy during different times in your life. Did it change over time?
Do you think that people have developed a particular view of you- because you stutter?
Describe the best situations/worst situations and what you think feel and do during this time and thereafter How do they differ?

What do you think are the least understood aspects about you and stuttering?
Do you/ did you talk much about stuttering - at home /friends/work?
When do you feel like you are negotiating stuttering successfully? During
which times in your life were these actions most useful? Why?

Interview Schedule Three

Purpose: To explore in detail specifically how and why participant's negotiated stuttering in their life contexts.

Guiding question: Tell me about how and why you have managed stuttering during your life time. Lets go back to some of the experiences you have told me about.

Did you do anything about stuttering at various periods in your life?
How do you negotiate the everyday communication - in varied contexts/partners.
How has this changed over time?
What are the most useful strategies?
Which are the least useful over time?
How and where did you learn to manage your stuttering
What were your experiences of formal treatment?
What were your expectations of treatment?

Interview Schedule Four

Purpose: To summarise, clarify and gain understanding of the most critical issues that should be captured in the life story as a consequence of the interview process.

Guiding Questions: What are the most significant aspects of your life I must include in telling your story of living with stuttering. Select the most critical events, the people and relationships. What must be in this story if it were to be shared with other people in general who would like to know about your experiences as a PWS.

How you describe yourself at various points in your life in relation to stuttering?
Are there any aspects you would like to talk about again?
These are the understandings I have generated thusfar: Is my interpretation reflective of what you said. Are there points of misunderstanding?
How do you feel having participated in this process. What were the easy parts? Which was difficult.
What did you like? What didn't you like?
Final closing comments.

APPENDIX G

SCHEDULE OF DATES, VENUES AND CONTACT TIME WITH RESEARCH PARTICIPANTS

INTERVIEW DATES & TIMES, VENUES

Participant	Venue	Interview Dates & time	Dates, time Story review & Discussion	Additional conversational time*	Total contact time
Siyanda	Inanda Library	12/5/01: 120min 19/5/01: 150min 24/5/01: 120min 31/5/01: 60min	First: 2/07/02 60min Second: 12/02 15min (telephone)	80 minutes	10.08 hours
Kumari	Local medical centre/ Kumari's home	28/7/01: 120 min 3/8/01: 120 min 10/9/01: 95min	First: 28/8/02 135min Second: 6/12/02 (email) 20 min telephone	115 min	10 hours
Gareth	Westville Library	1/3/01: 120min 8/3/01: 120min 20/3/02: 120min	First: 29/04/02 60min Second: 1/12/02 Via mail	25 min	7.42hours
Sagren	Westville Library	1/11/00: 90min 8/11/00: 120min 24/11/00: 120 min	First: 21/9/02 60min Second: 12/12/02-e-mail	40 min	7.17hours
Thando	University Interview room	8/5/01: 60min 15/5/01: 90min 3/7/01: 120	First: 2/8/02 60min Second: 28/12/02 via mail	95 min	7.08 hours
Nontokozo	University interview room	19/6/01: 60min 25/6/01: 90min 27/6/01: 90min	First: 26/06/02 45min Second: 28/12/02 via mail	120 min	6.75 hours
Hennie		18/9/2000: 90min 26/9/2000: 120min 9/10/2000: 120min	No feedback	20 min	5.83hours

* Time spent talking or meeting outside of formal interview. E.g. before or after interview there would be conversation when outside of the formal interview but were relevant to the research project. This occurred often while waiting for a venue to become available, traveling to and from a venue, telephonic conversations.

APPENDIX H

MEMO WRITING SAMPLE: INTERVIEWS

Samples of memo-writing /reflective notes: Excerpt from Interview Process

Prior to interview

I had known Kumari for a long while as a mother who had brought her child to therapy when he was very little. Very few people brought children as young as that. Through the years we had many opportunities to talk about stuttering and about life in general. So when I embarked on the research she was sure to be approached as a research participant. For two reasons –I knew her well, and she was female- I knew very few females who stutter. When I called Kumari about the interview she was just about to go overseas and she did agree but had lots of questions about what would happen- I explained in details giving her examples of some of the kinds of interviews I had done already – when I called again after that she still agreed but appeared anxious and once again I explained the nature and purpose of the interview- maybe I should talk –I have all these fears –maybe it would help. I wonder why she seemed so concerned.

First Interview

Kumari and I got into conversation. One could easily not recognise the stutter-conversation very easily-she liked talking and readily volunteered her story- she didn't appear to need any convincing at all. The flow was easy and we talked about many things – a lot off the record as we were leaving- another valuable 45 minutes of very general conversations which I really needed and she said she would go through that again. We had fun at the interview- we laughed a lot and I felt that perhaps it was her combined with my own experience that I felt as ease and let the interview run- as with many other interviews she kept asking if all of this was relevant to the interview. Kumari looked really good- radiant the best I had ever seen her- I even commented on how young and energetic she looked. It was all about her new way of life I discovered as we went through, it was most fascinating, she was certainly gong to teach me a lot about spirituality.

She was also very animated in how she spoke- she used a lot of gesture of which I noted – this was communicated part of the story which she didn't necessarily say in words- it was not possible to record gestures as it would be disrupted so I paraphrased what she meant to include the meaning of the gesture that was communicated to me. I also had written notes.

e.g/ her mother had certain standards about the person she should marry – she showed this by demonstrating and “elevated level”. Her speech was for most part fluent. The disfluencies were short blocks very transient in nature that did not disrupt the flow of conversation. She did indicate her awareness of the moment of disfluency and although not “comfortable” at that moment continued the conversation.

She on –many occasions – said that she didn't remember chunks of an unpleasant childhood. She thought that maybe she blocked this off and that these were maybe unpleasant times she didn't want to remember – however she was keen to ask her sister about some of the experiences- although the early childhood was traumatic Kumari was not emotional in the telling which was really good for me. Although because I would manage it- having managed with other people in my practice, I was

really concerned about how to manage this in the context of the research situation. Do I do exactly then same thing. How far can one go if someone breaks down crying.

I wondered why the interview with Kumari was so easy- and felt that the gender issue had something to do with it – we were both women with common issues as females, mothers, daughters and wives from similar ethnic backgrounds.

Second Interview

Kumari has talked to many people trying to piece together her early life. She seemed reflective and honest- she told me about how she protected her image, immaturity and early experiences as a mother. I think that is hard to do. Her life as a person who stuttered was certainly intertwined and relived after she discovered that her son stuttered. She appeared very self critical and really blamed herself for stuttering- I tried to offer other perspectives (I wonder if I should have done?). It is quite difficult to separate the interview from the therapy at times –however, she seemed to have grown as a person and that was her at that point- she has obviously come a long way- the conversations were close- about lots of intimate aspects and revealing her fears and anxieties.

APPENDIX I

SAMPLE OF INTERVIEW TRANSCRIPTS

Excerpt from Interview Two with Siyanda

- S: After the divorce. It was 1984. So then we didn't go to school 'cos now there was this. As I was saying, their influence, this negative influence to us for like talking about this "that you need not to go to your mum 'cos she's this and that". So they instilled that idea in our mind. So in such a way that it affected us you know in a great manner.
- H: Hmm
- S: we left school
- H: So you'll just left 'cos you'll couldn't..
- S: We couldn't, yes
- H: Both of you?
- S: Both of us, yes, both of us. She will ask us "Siyanda why don't you go to school?" "The school are closed". Now we had tricks to trick them.
- H: Oh, so they didn't know you weren't at school.
- S: Yes, they didn't know.
- H: Oh, okay.
- S: Now if we go back to Umlazi, then "Why didn't you go to school?" "No, it's this and that". So, I think by being influenced we also had the opportunity to misuse the opportunity like to have the tactic of hiding, you know.
- H: So you basically ducked and dived that time
- S: Definitely
- H: Didn't go to school
- S: Yes
- H: So you were just not interested
- S: We were not, we were not at all. Like to be given money to eat at school, so then we'll accumulate the money so that we go and look for the movies, be around in town during the schooling hours
- H: Hmm
- S: You know that was
- H: Bad times
- S: The bad times, yes.
- H: Siyanda I'm going back to earlier again and we'll come back to that point because I think that obviously was a significant time for you..
- S: And it's very touching
- H: Yes, I know
- S: I've lost almost two years
- H: Yes. You know when you were growing up in those very early years
- S: Yes
- H: Did you recall when the actual stuttering started?
- S: No, I think I was born with it.
- H: Alright, so..
- S: 'Cos I don't have, yes, yes, I don't recall.
- H: Okay and with your brother as well, you don't remember?
- S: Yes, I don't remember.
- H: You don't have a definite memory of it so you felt it was always there?
- S: Yes.
- H: And did your mum say anything about when she thought it started?
- S: Sorry.

H: Did your mum say like "I remember when you'll started talking when you'll were three or four" or when did she notice you stuttering?

S: I never ask her that question. I'm going to have to go back and her that question (laughs)

H: (laughs). Everybody does this

S: Yes, she was there for us. I remember one incident when I was doing standard one. One of the English teachers ask a question, you know then he ask the question and if you don't answer the question then you have to stand up. Like he asks me the question and I was in the process of stutter you know, so he hit me before I can answer him 'cos then after he hit me I came up with the answer. Then he say "why didn't you tell me before," no I was in this process of stutter you know. Then he went back to other teachers then he explained them the whole situation "you know there's this guy who stutter". I think he felt guilty for that ...

H: Hmm

S: ... 'cos he didn't realize that I was in sort of this process, so then he felt guilty or he yes he felt bad about that.

H: Yes.

S: So he went to the staff and told then that guys we've got these twins here 'cos we were doing the very same grade

H: Right

S: Yes, in the same class. So he went back and he told them that these guys, the twins Siyanda and Skumbuzo so you have to be patient with them 'cos they might be in the position of stuttering.

H: Right.

S: So I hit one of them so then I felt like I did the wrong thing 'cos if I had given him time - he gave me the right answer after I hit him.

H: (Laughs) Okay, so that was the first time that you remember an incident about your stuttering.

S: Yes, yes

H: Alright. Now I'm just interested before then, right.

S: Yes.

H: Because usually it tends to start most of the time when children are three or five

S: Three or five

H: You know, growing up in that stage. At that point you don't remember any talk or discussion or anything said about it?

S: No.

H: Okay, and from your mum...

S: Except that when like when there's this thing I think there's this connection between twins. Like if Skumbuzo is out of my sight so then maybe he's fighting there. I could feel that.

H: Hmm

S: And I simply just go straight to where he is. So I won't ask anything I'll simply carry on with the fight. (laughs)

H: (laughs) Wow, that's nice, hey. You've got another partner.

S: Yes, yes. I won't be in a position to discuss or to ask them what's wrong then I will be in the process of stuttering then I will be that much angry then I will just keep on... Same thing applies to him as well. If I'm in trouble then he will feel no something is wrong with Siyanda will just keep on looking for me. So if I'm in trouble he won't ask, he won't hesitate, just join the party (laughs)

H: (laughs) Come and join the party. That's nice. I mean who has the fun of having your brother know when you in trouble. Okay, so you would kind of have a communication between the two of you so you had a sense that something was going wrong?

S: Yes, yes. When we were still growing up but in nowadays it won't happen.

H: Not now.

S: Not now.

H: When you were little

S: Yes.

H: Okay so in that early time now before even school

S: Yes

H: You don't recall your mum saying anything or anyone in the family saying that you stutter or did you remember that, like for example did your mum think that she had to communicate with the ancestors about it, was there any ritual done? Anything around the stuttering?

S: Not at all. But there's this thing that she, I mean they still have to do. Like in the Black community if you are having a child you have to then tell the ancestors. We were the gift, the twins, in the family 'cos before she had twins but they both passed away, you know. So they were the eldest.

H: Right

S: They were the eldest. Is it oldest or eldest? The oldest. They were the oldest. So they passed away. So I think they still owe us that prayer because they didn't report us to the ancestors. But I think the problem lies with the financial matter like

H: Right

S: They even mention that guys you have grown up and you have to do that thing, that prayer for yourself.

H: So it's still a thing you have to finish, it doesn't matter when

S: Yes. If the mission is still unfulfilled so then (laughs)

H: But there was nothing, no talk about the stuttering or anything as you were growing up.

S: No.

H: But you recall at that age when you were in standard one

S: Yes, yes

H: Okay, were you and your brother stuttering at that time?

S: Sorry

H: Skumbuzo

S: Skumbuzo, yes.

H: Skumbuzo, both of you were stuttering?

S: Yes.

H: And both in the same grade?

S: Yes, yes

H: Okay, and then that was the reaction of the teacher at that point.

S: Yes, at that point

H: Do you have any idea of what the children, did they tease you? And you know when you were very young, still primary school, early days

S: Most of the time they used to tease us

H: Hmm

S: Like if they irritate you then surely you get angry then you stutter, you know. So I think that was one of the appreciation of being around with us (laughs)

H: (laughs) Alright, so what did they tease you? What would they say when they teased you?

S: Like we would have this thing they say "Siyanda you are in love with that particular lady, you know, like you have to date that particular lady"

H: hmm

S: Yes, yes. Maybe they pointing the ugliest one. Surely then you'll be "AY AYi, no I won't go out with that lady" so that was sort of a thing. And also like...

H: So, to make you talk and stutter.

S: Yes, yes and also if like we played soccer then if you didn't score the goal then they'll come to you and say that is why you didn't score the goal 'cos you've got this stutter. So when you are about to hit the ball you stutter so in such a way that your stutter affected your leg as well, you know (laughs)

H: What? So that's how they used to tease you.

S: Yes, yes.

H: Okay and what did you do, do you remember when they teased you?

S: To show them who we are you know, just to (claps his hand as if hitting someone)

H: So you'll used to have a good fight.

S: Ja, good fight.

H: Do you think the fighting had anything to do with the fact that you couldn't say your words properly?

S: Yes, yes, yes. That was the only response to show that what you said or what you did is irritating me.

H: Hmm

S: So I'm not in a position to cough it out 'cos now I'm angry, I'm stuttering then by keep on stuttering surely you'll laugh.

H: Hmm

S: Then they see that Never ever mess with me- then I have to show you then that what I'm made of (laughs)

H: Right, okay so that was the easiest way

S: Yes and also I think that also was the action. It was done by the father to our mum 'cos whenever you've got any problem the best way to react on that is to fight.

H: Right

S: I think that also had the negative influence like the best way to solve problems just to keep on fighting. But when the time goes by then we've changed. I for one have changed from that you know 'cos I've viewed or pursued the life on the other side you know ...

H: Sure

S: ...of the angle you know

H: And when you were at school now still you know maybe primary school how were you doing at school academically?

S: Oh, we were doing fine.

H: Hmm

S: And we were the best students when it comes to uniform. My mum was very much you know responsible for like ironing our uniform, having the proper uniform you know. And I remember one day when we were doing standard four we were even called in front of the school and then we were an example that "guys we've got two twins here that they are wearing the proper uniform can you also go back and tell your parents to buy the proper uniform." So here are the good example of the school 'cos usually we have the jerseys...

H: Okay

S: ... and the coat and the ties and grey trousers and black you know the proper uniform.

H: Alright

S: Yes

H: So your mum used to proud of...

S: Yes, yes

H: ...about dressing you and making sure that you were presentable

S: Yes, we were dressed to kill in terms of uniform, not a casual thing

H: Ja.

S: But when it come to school wear she was very much careful

- H: And with, in that time what were your understanding of your speech at that time?
I know it may not be as easy to talk about that because it is along time ago (laughs)
- S: Yes. (laughs)
- H: But did you think at that point it was a problem for you that children were teasing you and you were getting stuck and did you see the stuttering as a problem then?
- S: Yes 'cos I mean taking from the response that I had- when I was you know like when I was speaking to the people or person or like having the deep conversation with the person which might turn out to be the fight that was the only response, to fight. So I think that shows that it was a problem for me 'cos I had no other option

APPENDIX J

LEVELS OF INTERPRETATION: ALVESSON AND SKOLDBERG (2000)

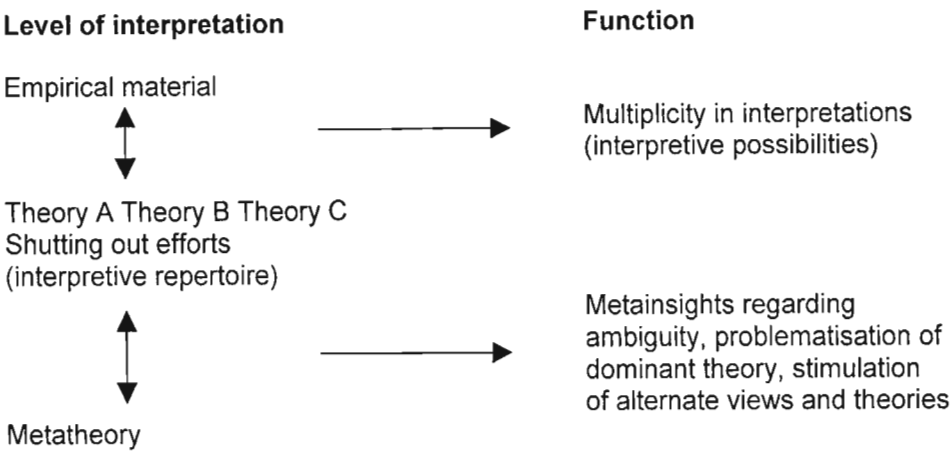
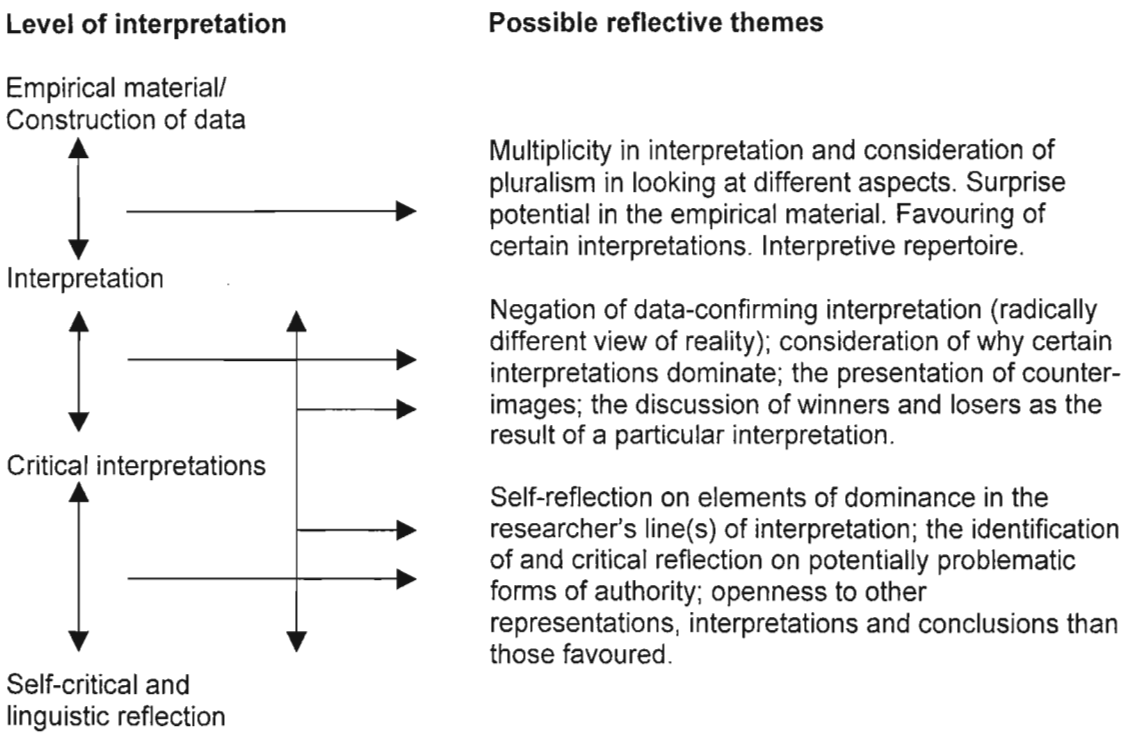


FIGURE ____: Possible effects of interaction between empirical material, interpretive repertoire and metatheory



Interaction between different levels of interpretation

APPENDIX K

CRITICAL DISCOURSE ANALYSIS

Ten questions to guide Critical Discourse Analysis (Fairclough, 1989)

Vocabulary	1. What experiential values do words have? What classification schemes are drawn? Are there words which are ideologically contested? Is there rewording or overwording? What ideologically significant meaning relations (synonymy, hyponymy, antonymy) are there between words? 2. What relational values do words have? Are there euphemistic expressions? Are there markedly formal or informal words? 3. What expressive values do words have? 4. What metaphors are used?
Grammar	5. What experiential values do grammatical features have? What types of process and participant predominate? Is agency unclear? Are processes what they seem? Are nominalisations used? Are sentences active or passive? Are sentences positive or negative? 6. What relational values do grammatical features have? What modes (declarative, grammatical question, imperative) are used? Are the pronouns we and you used, and if so, how? 7. What expressive values do grammatical features have? Are there important features of expressive modality? 8. How are (simple) sentences linked together? What logical connectors are used? Are complex sentences characterised by coordination or subordination?
Textual structures	9. What interactional conventions are used? Are there other ways in which one participant controls the turns of others? 10. What larger scale textual structures does the text have?

APPENDIX L

STORY REVIEW GUIDELINES

Guidelines presented to participants for story review process

Dear _____

The process thusfar

We have now reached the part of the process which requires a review of your story.

The following has occurred thus far.

We have completed our first set of interviews during which we talked about your experiences of stuttering. Thereafter the audio tapes were transcribed i.e. I wrote out what you said and what I said. I used the transcript, the tapes, additional material you provided to construct your story.

What is the story ?

The story has been written based on the meaning I made by listening many times to the tapes and reviewing the transcripts. I have presented the understanding I derived from during our conversations. Although I have actual words you have spoken, the story is based on my *interpretation of what was said between you and me*. It is therefore not a literal meaning. E.g. if someone said " it's five o' clock". I would consider the context of the conversation. He may not be just stating it is five o' clock. He may be saying/meaning that it is very late. Please ask me to explain further if you need to know more about this.

The most critical aspects of the story have been selected as they relate to the questions and issues I am trying to understand in this research project. Therefore, it may not include everything you said. It is broadly focussed on your experiences of stuttering and how you have lived with it from childhood to adulthood.

I have chosen the aspects, events and issues you emphasized as important for you.

I have arranged the story mainly in chronological order i.e. your experience from childhood to adulthood.

The story is written in first-person i.e. I have written the story as if it were you speaking. In the final presentation of the story in my research all the names will be changed. I have left them as you have told me to make for easier reading for you.

In some parts the story have been recreated or extended to provide a deeper understanding of what might have happened. In order to do this I have used fictional techniques i.e. the scenes are recreated to make them more real and informative.

It is a short story i.e. I have written a few pages to draw together the many aspects you told me about your experiences of stuttering.

Your next task

1. **Read the story** and after the reading write down your immediate reaction. Please be honest about how you felt.
2. **Read the story again** after a few days. Read the story for detail. Correct all inaccuracies. Delete what you think is unnecessary. The story conveys what your experience has been like. The writing techniques have been used to enhance the story-telling to make it interesting and provide emphasis. If these disturb or disrupt your story, please let me know. If there are any additions, deletions, changes, please record these. The entire story can be changed if necessary. The transcripts of the interview and audio tapes are available if you need to refer to them.
3. **Read the story in detail again if possible.** The next task is to abstract the meaning you make of the story. What are the most important aspects to you. There are no right or wrong answers. E.g. in the story of the three little pigs who build houses- the meaning and message is not about the houses only but also about who we can trust, who are our enemies. In the same way your story as a deeper meaning. Please let me know issues are most important to you.

After you have completed the story review, please do the following

1. Reflect on the entire process. The interview and the story review and analysis and then answer the following questions
 - a. What was the process like for you?
 - b. Have you changed or learned anything different during this process
 - c. Has this process made you change any actions, behaviours, beliefs with regard to living with stuttering.

Please write out your responses and we can discuss them when we meet.

You may call me at any time if you have any queries about this process. As soon as you have completed the task, I will arrange a follow-up discussion where we can discuss the story and your comments. Thereafter, I will revise the story as necessary and send you the second version for comment.

I have learned about many interesting issues from the process and look forward to your response.

Special request

I have a special request. Please can you assist with: (I presented details of issues I was unsure of and required more detail).

Thank you for taking the time to share your story with me. I am grateful for your participation.

Regards

Harsha

APPENDIX M

MEMO-WRITING: DATA REPRESENTATIONS AND INTERPRETATION

REFLECTIONS DURING 2001/2002

March 2001

Which comes first? How is this all done. I started with this process through other people in the group with Daisy producing stories and relating issues and with me raising concerns about whether is interpretive, critical, how does you carry meaning through the stories- how do you read the data and find what is important and relevant how do you write in relation to a critical question WHAT is the critical QUESTIONS/ S my eternal dilemma. Useful discussion, more questions than answers.

My first attempt –at the story pilot phase- wrote in third person did okay seemed interesting-raised issues of identity/power. Some how the issues of identity is central. I really didn't understand issues of voice well enough. Michael explained issues of persona in data representation. Now I understand better. I was writing the story in his participant's persona- I write the story in his voice-and declare this- I didn't know that before. I was worried because I thought it was fraudulent to pretend to be him. Now I feel better about writing in first person. Rubby explained it again and I understood also what it meant to co-construct the story and also to write interpretively. Rubby explained why writing creatively is important for research.

My first attempt was realist- wrote verbatim transcript –his words without too much interpretation. The realist/ positivistic debate is interesting. I must understand this better. A lot of the story was irrelevant- I didn't know what issues I was writing- It was experimental. I thought I had to write like Dickens- didn't seem that interesting. Then we did Farida's story of Anthony- Michael explained why that was good. Now I understood- what hit me and to keep it tight simple uncluttered get the meaning it also seemed easier to do that more spontaneous.

April 2001

Wrote two versions- second was better but I wasn't really satisfied. Tried again after writing 3 introductory chapters. These were more spontaneous and analytical Meshen helped a lot. Look for the big things, the social creations, fictionalize. Read Roy. I did and learned a lot about writing. She is excellent. I did the third versions by listening to the tapes and reading transcripts- back and forth till it felt better. I still didn't think I was really doing this well enough. Stats are much easier.

When I reached the end of my road with this story business I called Ruth- she read. we had a long 3- hour conversation about analysis and writing. She said- write what he means- not just what he says- big difference e.g. when he says joy- what does he mean keep focused on that. She liked the stories . You write well she said. She also explained how Fairclough could be useful for issues of words and style. I had to start believing I could I felt good end energetic and ready to go. She also helped with technical aspects. Capture his tone, write as he speaks- short sentences- cut out the clutter. Work with stories of success. I write better listening to the tapes than viewing the transcripts I used both. The actual words in the transcripts were useful.

Listen to the tapes; remember what Ruth said. Don't listen to the words only listen to what he is saying what is he meaning that's what I must capture. e.g. when someone says; Its five o'clock depending on the one of voice emphasis, loudness etc you get different meanings. It could mean a response to a question it could be that he is telling you it is getting late. So I use this and as I listen I make listen to the meaning. I am conducting an interpretation of what he is saying. First level analysis-that's what Michael said. But it does go better. I understand what I am doing better.

There are so many things they are saying and so much stuff. At this point it all seems relevant so I write complete stories. I will edit out later because the stories are representation tools. I will motivate this in methodology

Back to process. I make yellow stickers/ notecards as I listen. I still do detail because I am too scared I might leave something important out. Next step rearrange stickers into chronology and thematic clusters. Ask what is he really saying when he tells me about discovering stuttering at school then in a another page I write the main points. Six to eight events is enough. I do leave out aspects, seemed to be more focussed. Living with stuttering, that's what their stories are telling me about. I still don't know critical questions in a specific way there are there but need focus. I won't worry about it now. I will just ask what did they tell me about their experiences of stuttering in a general way.

After rearranging and identifying key aspects of what: what they say was important to them there are some bits that I did ask about- e.g more details about therapy. But I had to learn to follow their story that is the point I want to know their story I do shape the story but I do have to be careful that I capture what is important to them e.g. Dhevan's story family and forgiveness were important they did relate to stuttering but I had to find a way of linking them. The real challenge linking life and stuttering linking the disorder and life. It is not straightforward and easy but it is there because they are related. I make the links in the interpretation but I want to know from them whether these are plausible and adequate. The participant's reading is important. Their reading is a critical part of this process.

Feedback session with supervisors: Sept 2001

Who am I writing this story for, after the discussion with michael and vijay I am more threatened because I am writing for education. People who stutter? Or are we producing this together for professional, public, educators? Difficult one – multiple audiences but this project is direct at academy. I can use the stories in different ways later. Vijay reminded me that the process does not end when the project ends. But the project must end. I don't really know feel - a bit lost with this but remember Lather –there are more questions than answers. ...getting lost.. and that's a good thing too so why does not it feel so good. Everything in this project is creative, I am active, I am scared. I am not used to creating. But my research training taught me you had to be certain when you had the data you use stats these are the calculations you make. It is hard when you have that as your experience – when I write now I never know if its okay. I have never written stories in years how will I know it is okay. I wait for Michael. He says wonderful a good start. Meet with Ruth she says wonderful I feel better and so I do them spontaneously. I write what seems important to me and get the idea of stories better. I learn to write by reading. I read many novels. I read actively and write in my wordbook. It does give me freedom to really construct what events and feelings are like.

Most importantly it seemed to be an honest process. Creative did not mean make up. I use fictional techniques ala Gough. Noel was very helpful and I learned a great deal

from him. He gave me two articles by Barone on using fictional techniques. They were excellent. I feel more comfortable that I have a theoretical understanding of using fiction. I suppose I have some sort of style for each person to capture how they convey meaning. It is honest because I am putting on paper what they mean and they will have a chance to respond, change and scrap. I am really waiting to get their responses I think it is a fair capturing of what they said.

March 2002

This process is never ending. Ruth said to interrogate treat each one with suspicion. I do have difficulty doing that. I must learn how to. E.g. Gareth perfectionist wants to be powerful. I suppose that is so to a certain extent but there is always something in their more, human I don't know how to describe this. I know that romanticising isn't good. People do portray their best selves. But isn't it what we have been missing. Maybe that's okay that is how they would like to be seen everyone has told their stories negatively

I enjoyed the process. It was rigorous because I paid attention. Listened carefully wrote with care and will follow through with the process.

I often go back to the positivist process and this one as a way of understanding and explaining to myself what I am doing and where I am. The non-innocence of positivism is clearly apparent when I do this.

This process I call data management. What is the data. How is it managed

This project: the meaning we produced captures on tape and transcript through the interview process.

Positivist: data is the raw data numbers/ scores in most instances

Representing some process e.g. score representing central auditory processing performance

Data must be managed and represented in some way

This project: represented in stories : to maintain narrative richness and unity. To see meanings and connections.

Positivist: figures, tables, graphs

Draw attentions to main features/issues/findings

This project: select those aspects that are robust. Let the plot develop to illustrate main points

Use fictional techniques to bring out and maximise ideas/issues

Positivist: use stats to get measures of central tendency, standard deviation and stats to show what is not obvious.

Who does this: The researcher selects what must be done the researcher is an active participant

Other people can offer help, suggestions, different interpretations: helpful and useful. Does not mean they will all see the same things.

Words are wonderful but words have limitations so will we ever know the truth? Or will text be limited. IRIS said this is the movie. It will never be ultimate truths just working truths or functional truths to allow understanding but we will never know it all. I seem to understand many things better now. Narrative ways of knowing do help to

explore the fine and subtle aspects. Emotions are particularly important they come up in all stories and how people feel is conveyed but words also fail them they cannot put into words the feelings of extreme pain and panic.

Stories tell me about living with stuttering I have used a narrative knowing to explore their experiences of living with stuttering What understandings can I get by understanding their constructions and worldviews :How will it reduce my ignorance. I don't Think I must use the framing questions as critical questions rather frame them as lines of inquiry

Back to stories. Issue that surface –so many

April 2002 continuing

Interpretation ideas

Changes over time, critical events moments and turning points, fluidity,
Captures the personal/ social and the interplay
Many selves/identities
Constructions of stuttering, how it grew
Management strategies and various pathways to success
Emotions throughout: how do we know something: be feeling it ?thinking it and doing it. The feeling dimensions come through strongly
Relationships and power dimensions in everyone; power you *feel* power relationships within relationships, changing relationships.
Uncertainties and risks
There is so much I will have to choose

Ruth's advice. Don't let anyone tell you
Go through the painful process of figuring it out for yourself. I will do this
Sit for a week with the data stories and analyse. Renuka, her voice is ringing in my head. Immerse yourself in the data. It is a creative process. Thoughts will come to you. You will see things that no one else sees. Will it come to me .I don't know. This is difficult.

I am not confident I will do this but my learning will be from other places. I will choose at the end what I think will be the best thesis. But I will ask Mershen, Sandhya, Ruth, Michael and Vijay. Most important the participants of what they say is important to them.

The dilemmas or tetralemmas I have is that there are so many things I see and yet even if I take one view it will be okay. I am considering paradigms this is largely interpretive there see critical elements. Deconstruction, feminism and social constructivism all apply but not single. So moving back and forth and between may be okay. Mershen says write this out what you are feeling and through it create a framework of analysis and analysis and use this as first level. I will try I really don't have a creative mind therefore collective genius applies. I am cautious, I like to learn and be convinced myself before believing.

Critical may allow power and oppression dimensions allows for entry of political Interpretive. Does it have to be boxed. We are all over the place theoretically. Allows to understand the story but not critical enough, can be flat
Deconstruction; I like it but still need to figure out what it really means. Lather's advice- don't go there is you are a novice. Took her 10 years to figure it out.

Feminist; important but don't really know it that well. We have never been overtly gender aware. We just practice like men without knowing it. We always analyse everything according to the male norm. Now that I know this I see it everywhere. It is a man's world more than it is Black or white world.

Social construction; nice I like the idea of how society plays a part in creating and maintaining and influencing living. Gergen's work is nice. I must read more of it.

So where to now.? Something that must capture power, relationships and emotions since it seems that we have missed out these dimensions in creating theory about stuttering or living with it.

I like the idea of Othering or Dis-othering, essentialist – got from discussion with Mershen's- nice overriding concepts to include. Sometimes I think he understands this project better than me. Maybe it also has something to do with distance and of course his creative mind

Exciting stuff but I am so scared. If I put this down many would think that I am really lost and confused. Others would think it is reflexive. I think it is learning I will never know it all no one will and that a comfort.

The nice feeling is that at the end I think that the thesis –the knowledge will generate an interesting set of constructs that I will use for clinical work and teaching students. As Noel will say it would have reduced my ignorance. Theorising the mundane, the local –the things we know from our everyday conversations with PWS may seem simple but it is not. It must provide new thinking tools and language for speech-pathologists. Outside of this the public must get to hear these stories. Articles in newspaper ultimate it must serve some educative purpose

It is certainly a life education for me.

The important point is I did the stories. I conquered my fear there let me face the next one

I read a lot of literature in medical sociology and sociology. I really like that stuff. I have read so much outside of speech pathology. I really like sociology stuff.

Did the first analysis but I was strangled with a framework which was constraining and with my positivist ways of doing things. I wanted the facts in neat little boxes and I was losing direction. They didn't like the emphasis on suffering and alleviation. Too much emphasis on suffering. I felt this was an important part because even as clinicians we never listen to this dimension of the story. I needed to focus on dimensions of agency. Thank god for supervisors. They put me back on track. It was very difficult. Not the meeting with them. I just felt like I had to go back to the drawing board. Michael said just let the data influence you. It is very hard to be creative and I just wanted to give this whole thing up. I had some nice ideas for clinical practice. Of course I couldn't do this

Sept 2002

Back to the drawing board. This time, me the data, and the metatheory. Refocus they said (supervisors) on the bigger intentions of the project. The trouble was that everything I had to present was new and I was still scared. I supposed that I will be scared even when I hand it in. I began afresh and did what I thought was right.

I waited for feedback. If it was negative then maybe I needed to rethink whether narrative research is for me. The old boxes are easier for me. Michael said it was fine. He liked the analysis and suggested where I could make changes. Waiting for Vijay. Michael likes creativity. Vijay is hard core-give me the facts. A good

combination-they are like the two sides of my brain. There another dichotomy! We never leave our past behind.

This analysis is the hardest thing I have ever done. I have used I like it. I felt that there is some good theorising I can offer to students and nice practical applications. I like it sometimes but each time I look at it I want to change it because I see something new. It is a project- it must have an end- When, I can't wait I am running out of creative energy. Is the end in sight?

October 2002

I completed the next version of analysis. It was really hard. Hanged everything. Used the self and identity as central issues. Did an analytical tool which was developed dialogically- I had been talking to Ruth. It is a useful framework. Ruth was said the contribution was new and exciting. Something she didn't think about. It was the kind of knowledge practitioners need. Mershen said it was a good empirical analysis and he liked the thesis and helped to problematise some issues further. I didn't know how to evaluate it. I had worked with this for so long. I found nothing nice or new. I suppose this is what happens when you are too close to something for so long.

December 2002

Michael reviewed and provided some suggestions about how to develop the analytical framework and he liked the thesis offering. I couldn't believe it. It seemed that the end was in sight. I will wait for Vijay's feedback. In the mean time I will give it to some of my colleagues at work to read so we could discuss the clinical implications I want to present in Chapter 7.

25 December 2002 yes –it's Christmas. The children are asleep and I have some time to work peacefully. It 's hard work and I have no creative energy left. No one said it would be easy. Renuka said if this level of work did not change you then how worthwhile is it?

APPENDIX N

SAMPLE OF INDIVIDUAL CASE ANALYSIS

Commentary on Hennie's story

Suffering: What are the conditions /forces which generate suffering?
I don't like the term suffering. Need to find a better way. Will use it for now

Over his life time

Although Hennie discovers that his stuttering at a young age (8 years) he does not tell of suffering during this time. The first telling of suffering occurs during his transition into high school and thereafter interspersed through high school. During these years his frustration grows but he does not tell of an extreme suffering. In this context his awareness of being different compared to his peers is amplified at a time when he and his peers are developing and in a process of maturing and creating new awareness of themselves. The stuttering is then amplified because it is problematically different and obstructing him from developing an identity that is in concert with his peers. The image places value on being with the "In" crowd competitive, popular and having good at least normal communication. His friends draw attention to this difference although in a friendly way.

In University years the suffering is diminished and appears to remain in the background. There is concern about the possibility of having to speak but that remains a remote possibility. As Hennie enters the world of work there is growing concern about his stuttering. In the early stages of his career his concerns are growing but he appears to cope better. However, as the stresses of running a business and the attendant stresses of daily life mount he feels more burdened and the suffering emerges as part of a conglomerate experience. However, Upon deciding on a definitive career path the suffering is amplified because he perceives it as an obstacle in realising his dream.

One had to then examine what is the nature of this obstacle and why is it perceived as an obstacle. There are many aspects to this. Firstly, there is frustration about the actual nature of the problem. There is always concern about when it will occur prior to the communication. It is involuntary in nature and though expected has a surprise element to it. The actual moment is constituted as a moment of being "Blocked" where the word does not emerge and there is an ensuing struggle to get out of the block. The struggle itself generates an impression of struggling and contortions of the face none of which occur as part of normal, fluent communication. The message is then conveyed in a minimal form and unsatisfactory form. All of this has unfolded in the presence of the Other which generates embarrassment and frustration and shame. The loss of identity as a normal person is threatened and he struggles persistently to regain a sense of normality which often fails. Because Hennie is able to be fluent he tries to do so but this generates suffering because of the great mental attention devoted to how to say the word which is usually automatic. As a consequence the word choices are often not suitable and therefore impacting on the message. The entire episode is accompanied with a battery of negative emotions. There is an extreme sense of feeling "stupid" i.e. of not knowing because the communication has been disrupted.

The repeated nature of the event and apparent feeling of helplessness as a consequence of failed attempts alleviate the suffering generate great worry. The

recent dreams about stuttering provides an indication of the extreme extent of distress he feels. Therefore the suffering generates beyond the actual moment as Hennie tells of himself as an abnormal person. However, the context is of importance since there is a particular context that generates this concern. The social context and the work context. The social being a regular situation and the work context being one of the future.

Hennie's suffering arise from the concern that he enjoys socialising but is becoming less social because of the stuttering. Although the people he socialises with frequently are less of a problem, he is concerned because the repeated and long interruptions generated by stuttering will reinforced his identity as someone with a communication problem. In the anticipated work context his concern arises in a context that is very competitive and where one has to communicate effectively to become successful. Here is faces the most difficult communication partners –the white, male executives. That white male executives are powerful is a contextual issues where the economically-driven enterprise in South Africa is predominantly White and male. There is also concern about the "presentation and packaging". The overt communication performance- the speech must be at least a normal aspect along with a host of other aspects that will help him to be a successful business. Hennie also sets himself apart in aspiring to be "better than" the rest highlighting the critical need to have the skills to be competitive. The suffering is generated from the concern that he may not be successful with this career.

The suffering is also generated from the many attempts at alleviating the problem and failure at being able to do this. Although he had attended therapy and tried a variety of skills he feels that he has failed to use techniques and the problem has grown. He has reached a point of being in desperate need of help and feels that he is suffering because of the excessive pressure he places on himself to be normal. In this context he finds the strategy of advertising suggested in therapy very difficult. Concern about how people might evaluate him solely on the basis of his stuttering.

Alleviating, coping, surviving

When Hennie began to stutter he does not tell of any suffering. His first formal attempt at reducing stuttering was generated via concern by parent/teacher. He was not concerned about stuttering and does the attempt did not reduce the stuttering in any significant way. However, as his awareness of being different emerges he tries to remain popular in an effort to belong and maintain contact others. He uses his sense of humour to establish and maintain relationships knowing that the stutter has the potential to set him apart. In high School he draws on these resources to remain part of the group. As a consequence of being popular he also gains positions of power like being prefect, sports captain and Leader of the Marching band in turn improves his social standing and his self-esteem. He is aware of how to be part of the social scene at school and as he gets assistance from a friend to talk to girls. He remains in the network by drawing on his resources like being helpful and reliable. He finds teachers supportive when they ask him to read occasionally. He expands his vocabulary to enhance the knowledge that he has and this he finds empowering. In University Hennie continues to draw on his social resources to remain part of the group. His fun-loving personality and participation in activities of studying, playing sport and socialising which retain his position in the social group. His concern with stuttering remains. The ability to foster relationships is evident during university years where he meets his wife.

Hennie also tells of assessing each situation and choosing the strategies to manage retain a face or normality. The strategies also include avoidance in an attempt to

preserve a normal identity but generates frustration at not being able to contribute to discussions on occasions. Keeping normal by avoiding stuttering by changing, swapping and chopping words Although this is a coping strategy the outcomes are not always favourable especially if used consistently over a long period. In the work context Hennie draws on his knowledge to continue the job but limits the communication to those speaking when he has to. As the boss in the moneylending business he established good relationships with his employees and with his clientele. Being in a position of feeling more powerful also lessens the burden of suffering. Stuttering occurs less frequently in this context but he does not continuously attach negative meaning to it. When he is in positions of leadership or authority like in the Marching band and prefect and captain he feels more empowered.

His attempts at therapy is primarily focussed on changing his fluency. These strategies have an impact for a short while but he is not able to sustain the effort. However, he does believe that improved fluency is important. On bad days he does try to change emphasis and do things that relieve his suffering. However, sometimes he vents his anger and releases his frustration by swearing at points of extreme frustration. At the Support Group he finds alleviation in meeting others who share his problem and feels better knowing he is not the only one. There is emphasis on looking to the positive aspects of his life like his family and friends etc. which he starts to focus on. He has also decided that he requires self-confidence as a way of building his self-image and embarks on a plan to attend a course which he thinks will help him.

Although he suffers greatly he does take steps to cope by considering alternatives and also through reviewing where he might have not put in sustained effort.

The strategies are situation-determined over time and may be immediate responses in a given changing situation.

He is also able to cope because it is not an intensive struggle all the time and there are times like when speaking to parents, friends and family there is little suffering.

The reactions of others to stuttering is important.

At the end it becomes his problem as an individual and something he alone must sort out although it occurs at a communicative interface

He has the skills and resources to start his own business and he does recognise that he has potential to be successful. He also has the ability to reflect on where he might not have put in effort (e.g. not practising fluency skills) and how to improve his own situation e.g. considering the issues of confidence and drawing on resources he think might help.

In the story as a whole we learn of suffering and the conditions which generate it and attempts to cope with it. The overwhelming sense of suffering that currently prevails tends to mask the attempts at coping/ alleviation. Despite the difficulty he still battles on indicating that although he struggle he still persists with the process of staying in the communication. He has a sense of self that is normal and able and witty therefore indicating his awareness of his positive attributes.

What assets does Siyanda tell me about?

ENABLING IDEOLOGIES

Interests	Specificities	Examples
1. Self Development		
Emotion	Empathy and love	Siyanda and his mother share a relationship based on empathy and love. He is empathetic towards community members who live in conditions of poverty and disempowerment.
	Confidence	Siyanda develops feelings of confidence about himself on stage. He carries this through a variety of contexts involving work and socially
	Composure	Self-defined feeling of feeling good/confident having done the right thing (value-based)
	joy, peace happiness, contentment and hope	Making choices and pursuing activities that are emotionally satisfying e.g. pursuing mission of being a community educator. Despite the many hardships Siyanda pursues his mission and is hopeful about the future.
	Managing negative emotions	Acknowledging that negative emotions are part of life Siyanda tells of how these are recognised and reduced within a short space of time to reduce the disruptive effects
Philosophies and cognitions	Gaining power over/fighting back	Fighting with others (physical violence)-although evaluated later as problematic Retaliating –domestic abuse Using English – although he is aware of it's potential to disempower
	Escaping reality/seeking refuge for threatening situations	Escape/avoiding situations considered threatening and problematic as children
	Strategic life choices	Making choices and changing direction at critical points e.g. changing jobs, choosing to go back to school
	Risk assessment in face of uncertainty and potential threat/ relying on intuitions	Making choices that involve risk but eventually allow for “taking chances” e.g. taking the audition, speaking in class when essential- doing what feels right in the many communicative situations
	Persisting	Continuing to struggle despite the many problems e.g. failing matric, poverty, stuttering

Interests	Specificities	Examples
	Reframing	In the face of prejudice and discrimination Siyanda challenges and reframes common views on race and stuttering and to couch them positively
	Connectedness	Being in touch with oneself and others runs strongly in the story as Siyanda pursues social contact and networking in many ways. Another level of connectedness is the mind-body-soul connectedness as he tells of drawing on ancestral guidance and his soul being in peace.
	Values	The values Siyanda ascribes to are evident. The values of democracy, equality, respect Recur. Valuing people and partnerships remain dominant in the story
	Wisdoms	Siyanda has guiding principles he collects and generates during his life time e.g FAIL ; as a means of supporting his own development.
Social Affiliations and Alliancing	Playing soccer	Siyanda tells of playing soccer in a community/country where soccer is a popular sport
	Leadership position	Siyanda takes on leadership positions in the Youth Interaction Committee, as Director of Sabona Khona and at school and within the community as spokesperson and educator
	Membership in Youth Interaction Committee	He attains membership in the group that is outside of his immediate committee
	Director of Drama Association	Siyanda is starts the group and positions himself as director
Communication and Socialising	Emotions to communicate	Siyanda regards emotions as an important base on which to communicate and connect- as evident on stage and sensitivity to emotional aspects of communication
	Assertiveness	Siyanda draws on this range of skills when he communicates in particular contexts- e.g. leadership positions
	Stage techniques	Siyanda draws on a variety of techniques to enhance his communication viz.modulating loudness, pace and tone of voice, breath control mainly on stage
	Collaborative communication	Siyanda views communication as a collaborative effort and therefore attempts to establish relationships by getting to know people, equalising and adjusting perceived power imbalances, and uses a notion of democratic participation

Interests	Specificities	Examples
	Multilingual advantages	Siyanda speaks three languages and uses these as an advantage for communication and as a strategy which helps him to manage stuttering when necessary
	Active networking	Siyanda actively seeks to forge relationships and networks as this skill is essential to pursue his mission.
SOCIAL SUPPORT	Social support via significant others	Siyanda receives social support via significant others who include teachers, his mother, his twin, his friends and community members. His mother appears as the dominant support figure
	Recognition by Others of skills and ability	In addition to providing support at times of difficult Siyanda tells of acknowledgement of his ability by significant others including his mother, community members, peers, his mentor and the positive accolades he receives in America
	Institutional Supports	Although Siyanda did not pass matric he did gain access to education and in particular values the access to literacy and English language skills he received. The Durban Youth Interaction Group provided a skills base that he values.

APPENDIX O

MEMO WRITING: STORY REVIEW FEEDBACK AND ANALYSIS

Gareth's Story Feedback

I completed the end of the story writing process feeling glad that I put on paper a story after all the learning that I had done. I felt really in need of comment there is no right and wrong way but there must be criteria for what constitutes a good research story. Vijay's theory helps because it provide guidelines and does make a case that researchers can write and separates the artistic issues from core content issues. I wanted feedback where and from whom- gave them to Mershen, Vijay, Michael and then decided it as time for the participants story. I would certainly benefit feedback nut decided to change/ revise stories after talking to all rather than piecemeal.

I gave Gareth the story first –in the order I had prepared them. After I gave them then I started to feel apprehensive- wondering how he would feel reading how I storied the story- what if someone else read it –close to him. I suppose those anxieties are healthy and I didn't want feedback that just said it was fine. Gareth was the first test and perhaps with his background in literature he is very able to offer a in-depth review.

Feeling apprehensive but ready to learn I met Gareth. As usual he was very jovial and- as a consequence of his conscientious nature prepared two pages of critique and discussed each paragraph in depth. I listened out for the comments offering comments I though would support the discussion.

Gareth was very aware that this was my story of his life. He allowed for my comment and left final decisionmaking to me. I listened intently as they were most insightful and they raised issues I had never been aware of e.g. my own cultural style of writing someone died/passed on.

He was great at grammar and pointed out all the errors and inconsistencies.

His comment overall was that the story did capture the main issues but that there were parts where he didn't see himself or see a point as I did. These were subtle and we talked around those for clarity and I will have to make choices as they best answer my research question but at the same time did not want unnecessary distortions for the purpose of my own theorising. I realised that I had carried some understandings through other stories and didn't capture enough of the subtle shades of difference. E.g. Gareth's parents- portrayed harsher than they were.

Gareth also raised issues of how "Smarty pants" was integrated into a story and that it would be only in a one to one meeting-I need to change that. He wouldn't do it in a group situation..

Drawings rather than paintings- terminology

In that era they didn't eat chocolate and did ride bicycles. He explained. I drew attention he race more that he did- however he understood the reasons for this after our discussion

It was an incredibly useful meeting because the interview also continues with Gareth refining descriptions and arguments –real fine tuning. He explains and clarifies well with example so I know which aspects I can enhance.

He did offer short comments on analysis issues but I really think that the abstractions will be researcher generated/constructed. He said we are more than just PWS. This is the one thing he would like to see in an analysis of his story.

He also took things off that didn't sound right on paper e.g. pansy subject yet it was the words he used in the interview. However, he explained that to see your story in print is a very different issue.

Gareth was interested in the research and listened to my talking about it –he realised just how difficult the process for me given the traditions of research are very different to what I am doing. We had a lengthy conversation about this. I felt really good because I had given the project much more perspective. Maybe I was something I should have done more in preparing participants for the interview process.

I will have to take all comments, listen to the interview tape when I am ready to rewrite with all comments I received. Grammatical aspects are a must- I need to make decisions about switching tenses.

I felt like this was really useful active respectful participation where we did understand where the other was coming from. I will certainly modify to make the story a better co-construction.as the purpose was not just to hear- but to change.

I felt that this was very thorough useful feedback and in a way I feel relieved and that the process had unfolded in this way. I could actively revise the story.

29/04/02

APPENDIX P

TRANSCRIPTS OF ON-LINE CONFERENCE

Transcripts of Online Conference conversations about narrative methodology
Conference : You are not alone : Transforming perceptions, October 2001
Chair: Judith Kuster
Invited Paper : Kathard, H. Narrative as a research tool in stuttering.
Website: <http://www.mankato.msus.edu/dept/comdis/isad4/isadcon4.html>

A refreshing new direction

Narrative As A Research Tool: Application Research In
Stuttering

A refreshing new direction

From: Jonathan Bashor

Date: 10/3/01

Time: 12:31:26 PM

Remote Name: 209.180.243.168

Comments

I liked your paper a lot. I'm gonna read up a bit on this "narrative" theme. What a pleasant change from the approach of the guys in white lab jackets. This really blends well with the existential psychology of people like Rollo May and Viktor Frankl.

Re: A refreshing new direction Narrative As A Research Tool: Application Research
In Stuttering

Re: A refreshing new direction

From: Harsha

Date: 10/8/01

Time: 2:17:32 AM

Remote Name: 196.21.162.250

Comments

Dear Jonathan sorry for taking so long to get back to you thank you for your comment - life history has had limited application as research tool and for me it does allow opportunities to engage with issues that are of direct relevance to clinical practice. it is also encouraging to get your positive comment because there is some risk taking involved when stepping outside of the traditional research domain I value this opportunity to dialogue further in the context of this conference- would you like to comment on why you consider it refreshing perhaps?

Re: A refreshing new direction Narrative As A Research Tool: Application Research In
Stuttering

Re: A refreshing new direction

From: Jonathan Bashor

Date: 10/8/01

Time: 7:27:44 AM

Remote Name: 209.180.243.116

Comments

I find it refreshing because I think it allows the narrator an opportunity to tell what role stuttering has played in his life and what it really means to him. Nearly all other research approaches on stuttering try to look at stuttering "under a microscope", removed from the person who stutters. I'm not saying all other research should stop, but this narrative approach is a new and welcome dimension.

Getting people to tell their stories Narrative As A Research Tool: Application Research In Stuttering

Getting people to tell their stories

From: Judy Kuster

Date: 10/7/01

Time: 3:03:43 PM

Remote Name: 206.11.82.27

Comments

Very interesting article!

Getting people to tell their stories must be a very interesting process, Harsha. Is there a somewhat structured or formal way this is being done? Some of us as professionals need to be trained to be better listeners I suspect! Good listening/counseling skills would be a real asset.

Judy

Re: Getting people to tell their stories

From: Harsha

Date: 10/8/01

Time: 3:23:09 AM

Remote Name: 196.21.162.250

Comments

Dear Judy

Thank you for your question/comment as a research tool lifehistory interviews have a rigorous approach to interviewing which perhaps most of all challenges the interviewer to be very good listener - It is really about "giving ear" to the person listening than giving voice to the person speaking the "good listening" aspect has to be problematised in the research context especially in a discipline like ours where the person is speaking with disfluency/stuttering .A very special learning experience/challenge for me was to listen past the disfluency. By virtue of my own training that expects of me to focus on the symptomatic dimensions of stuttering, I initially found that I was listening/counting and trying to make sense of the speech behaviour-tuning in to disfluencies - In order to listen past that or negotiate meaning within the framework of disfluency- I found that listening to the content and actively participating in meaning-making helped a great deal. In effect I had to become a co-constructor of knowledge and this can only be done if you really listen actively life history also requires good listening in that it is not intended to be a strict administration of an interview schedule- i.e. answer these questions - tell me what I want to know . Rather it is framed as "I would really like to listen to what you have to say" the climate of trust, power mediation etc are important aspects to consider as this is a communication process. There are some references I have included on life history methodology (Hatch &Wiesnieski) which has more on interviews and listening You have been interested in stories as well(I have questions I would like to pose to you in the context of your paper which I will send to you) However, I would really like to get your comment about using stories/narratives for the purposes of research.

Thank you Harsha

Nicely done! Narrative As A Research Tool: Application Research In Stuttering

From: Ken St. Louis

Date: 10/8/01

Time: 11:39:53 AM

Remote Name: 157.182.12.51

Comments

Dear Harsha,

I have just taken the time to print out, highlight, and read carefully your outstanding article. You have reviewed some very important concepts as they relate to cracks that seem to be appearing increasingly in the paradigms of our dominant science as it relates to stuttering. Walt Manning and others has begun to mention some of the same concerns in a forthcoming article. I must confess I am more comfortable in the traditional paradigm than in the realities of qualitative research, if for no other reason it is clear when a study is finished! Nevertheless, as you know, I agree with you that it is time that we begin to listen to people who stutter if we wish to truly understand them. You graciously referenced my new book that has 25 narratives told by people who stutter, indicating that such stories have been regarded as anecdotal pieces outside of a clear research frame. Interestingly, I *began* the project from a research perspective, trying to use qualitative strategies to uncover some valid and reliable hints about the range of real experiences, negative to positive, that stand out in the minds of people who stutter. I am still in the process of carrying out lexical analyses, content analyses, and theme analyses, but none of them seemed to capture the richness of the narratives like simply letting them speak for themselves. That is precisely why I wrote the book. One question always nags me, though. How can we be sure that our lens (e.g., your notion of "plotting" the life history narrative into a "story") does not distort the meaning that the subject (stutterer) intends? For example, unlike the negative themes identified by Corcoran and Stewart (1998), many of the stories that my subjects told were more like your examples from Nhlanhla. Stuttering, though experienced as painful at certain parts of their lives, served a much larger purpose as motivator, teacher, or challenger to become better, stronger, more caring persons. Depending on how a researcher/clinician characterizes a person's story, her or she might miss the critical difference between such concepts as "suffering" and "sacrifice" or "knowledge" and "wisdom." Any more ideas on how not to misrepresent a person's true meaning in narrative research? Ken

Re: Nicely done! Narrative As A Research Tool: Application Research In Stuttering

Re: Nicely done!

From: Harsha

Date: 10/9/01

Time: 9:00:44 AM

Remote Name: 196.21.162.250

Comments

Dear Kenneth

Thank you for your comment i am going to address some of the issues now in the best way i can and will come back to you if i think of more things to share I consider myself as novice and narrative research has opened up more avenues for questioning than i ever imagined. I do remember our previous communication -you had begun the the project as research-i agree that to do reductionistic analyses does really lose richness. Therefore the strength in the way i have approached it is to retain narrative structure at the data collection and data representation levels. i.e. the result of the project is also a story but to answer specific questions that the researcher might have. A story on its own is powerful but does not constitute research unless theorised - although this is also contested. The issues of distorting the meaning is an important one that can be managed in a variety of ways. The way in which i have managed this is to allow the participant to provide me with feedback regarding whether this is an authentic representation of his story However an important aspect to bear in mind

that the story or meaning-making process is a co-construction between the researcher and participant his story does not have meaning until i interpret it- one of the values is that the story may have multiple interpretations because it is not intended to produce hard facts- the reader of any story is also the interpreter- just as the researcher in any study chooses how he wants to interpret his data- extending on some aspects - therefore any two researchers can never generate the identical outcomes even if asking the same questions- research is a human process and all knowledge is tentative also the project is interested in subjective knowledges - so the characterisation often portrays what the participant wants to tell - the researcher may construct the story to signal this intention but will also capture ambiguities and nuances in the construction of the story -the researcher then has the responsibility to point out the contradictions or possibilities for alternative representations. As readers make different and multiple meanings of texts so too can the researcher- the researcher may ask other researchers to offer their comment as a check for convergence or divergence if ideas - like we may all see different things when we read graphs- true meaning does not exist - all meaning is constructed - the issue of misrepresentation is ofcourse an ethical issue and that is a whole other debate. The difficulty with making sense of narrative from a traditional perspective is that they have fundamentally different beliefs and assumptions about the nature of research - the issues of credibility however etc must be raised when engaging with research of any nature.

Stuttering:Narrative As A Research Tool: Application Research In Stuttering

Stuttering

From: Ellen-Marie Silverman

Date: 10/8/01

Time: 5:44:01 AM

Remote Name: 172.133.151.65

Comments

Thank you for your cogent presentation. You have reminded us all that stuttering as a disorder of human communication is more than an operational definition of problematic behavior. The problem of stuttering involves feelings and perceptions. And these influence the capacity for fully embracing the human experience. Recognizing personal stories as a compass for life change provides an incredible gift for those seeking release from problematic behaviors, beliefs and feelings.

On a personal note, I wrote a novel for readers 9-12 years of age, Jason's Secret, published this year, to allow both children who have stuttering problems and the adults who care about them to experience the feelings and beliefs of a 10 year-old with a stuttering problem. I believe fictional stories can heal, too.

Re: Stuttering: Narrative As A Research Tool: Application Research In Stuttering

Re: Stuttering

From: Harsha

Date: 10/9/01

Time: 8:20:09 AM

Remote Name: 196.21.162.250

Comments

*Dear Ellen-Marie thank you for your encouraging comment
the power of story is undeniable. At a recent discussion I had with fellow research colleagues
it had become clear that fiction is in fact more ""true" than fact -it tells more of the real story -
and the coining of the term "factional" also seems to reveal this
The so called "hard facts"" hardly ever illuminate as much as stories do and certainly never
tell of a comprehensive reality*

Comments and questions on your application research article

From: Jodie McGough

Date: 10/8/01

Time: 1:57:16 PM

Remote Name: 64.12.102.177

Comments

Harsha

What a wonderful and interesting new approach technique! I would find it very educational to read those PWS personal stories. It would allow others to get a better understanding of how PWS cope, and what they go through on a daily basis. Do you find it difficult to get people to share their stories, or are they eager and willing to do so? In getting them to share, are there specific questions that are asked in which they answer?

The one comment in the article that I felt was the most impacting for me was the statement "Research modeled along the underpinnings of the medical model has engaged primarily with the pathological, symptomatic dimensions of dysfluency but does not have a metric for understanding the fundamental issues of hurt, pain, grief, hope and encouragement the human dimensions of stuttering experience."

That was a view I never thought of until reading those words.

I found this article to quite informative and it allowed me to look at research in a different perspective. What a positive change in research!!

Thanks! Jodie

Re: Comments and questions on your application research article
From: Harsha
Date: 10/9/01
Time: 9:14:16 AM
Remote Name: 196.21.162.250

Comments

Dear Jodie

*Thank you I really feel encouraged about using new methodologies
It has not been difficult to find people to share stories in general - however i am aware that people through my own research that some have not wanted to participate- it is a challenge that narrative researchers face and must be problematised- alternatives include writing e.g biographies etc looking at pathological over dimensions has been our fascination and somehow the issues of pain grief etc - because they are not overt are convenient to dismiss and pretend that they dont exist - our traditional research methods are suited to those which priveledge the dimensions of what we can see- there is a whole lot more that makes up living with stuttering - hence the need for new methodologies.*

*I would really like you to interrogate for yourself "Why you never thought of it like that until you read the words"- it is the same questioning i have done for myself when i read the words - please share that response with me - if you feel up to it
regards Harsha*

Question @ Narrative Research

From: M. Crockett, Southern University, B.R.,La. Graduate Student
Date: 10/14/01
Time: 1:45:34 PM
Remote Name: 205.188.192.43

Comments

From your experiences using this research tool, are there any known disadvantages or concerns that one should be aware of before considering using narratives as a research tool?

Re: Question @ Narrative Research
From: Harsha
Date: 10/15/01
Time: 2:52:22 AM
Remote Name: 196.21.162.250

Comments

Like every other methodology narrative has its own disadvantages and set of concerns these may include that not all people may want to participate it cannot answer all questions- i.e. research method must suit the question and narratives cannot answer all questions- the disadvantage would be its inappropriate application it is not an easy methodology and there is a chance that a researcher who is not well trained in the use of the method may not use it to its full potential

An inspiring paper
From: Catherine Power
Date: 10/18/01
Time: 2:12:17 PM
Remote Name: 198.54.202.4

Comments

I am a stutterer and a Speech Therapist from SA (only qualified last year from Stellenbosch). I found your paper most inspiring. It really made me think and question many aspects of stuttering and stuttreing therapy. I would really like to learn more about your intriguing narrative research. I will be sending you my life story to your e-mail address soon.
Catherine Power

Re: An inspiring paper
From: Harsha
Date: 10/19/01
Time: 3:12:27 AM
Remote Name: 196.21.162.250

Comments

Dear Catherine

Thank you for your comment. I would love to hear your story especially because of your professional background. please e-mail me and I will send you some questions to answer - this will give you some insights as to what a life history interview is all about. i really look forward to hearing from you. Regards, Harsha

N. Bayer-graduate student : Narrative As A Research Tool: Application Research In Stuttering

N. Bayer-graduate student
From: narrative research
Date: 10/19/01
Time: 2:18:41 PM
Remote Name: 205.188.199.172

Comments

I like the idea of narrative research. I think speech therapists can get a real picture of the emotions the stutterer is experiencing.

Re: N. Bayer-graduate student: Narrative As A Research Tool: Application Research In Stuttering

Re: N. Bayer-graduate student
From: harsha
Date: 10/22/01
Time: 2:26:13 AM
Remote Name: 196.21.162.250

Comments

*Dear N Bayer
narrative research is especially appealing to clinicians because it allows for engagement with the issues of emotion and context- of whole lives- which clinicians must deal with
Harsha*

APPENDIX Q

ANALYSIS: PERSONAL EXPERIENCES OF PHENOMENON OF STUTTERING

Experiencing The Phenomenon of Stuttering: contributions to self-identity as DisOther

1. PERSONAL EXPERIENCE OF STUTTERING AS A PHENOMENON

Uncertainty and loss of control
Extended moments
Communication in jeopardy
Constellation of negative emotions and evaluations

Loss of control and uncertainty

Stuttering disrupts speech flow. This disruption described as block/struggle is constructed as an involuntary and uncertain event that generates a sense of uncertainty and loss of control. In each story there are descriptions of how the stuttering event unfolds.

Gareth uses the analogy of being on waterski's: The funniest thing is you will never know until it's upon you. Then you know. Oh! My God. There's a block. I didn't know the block was coming. BUMP and you fall and the block happens. It's a devil of a job to get going again.

Hennie tells of the unpredictable nature of stuttering: Then it happens. Out of the Blue It takes me by surprise because you don't know exactly when it will pop... You're not in control of your mouth and that is really annoying me.

Thando: I try to control the stutter but I can't.

Siyanda: The tongue and brain just don't connect. You don't know when it happens.

In each instance there is a feeling of losing control of the speech mechanism. Why does the feeling uncertainty and loss of control generate a sense of being Other? Participants tell of the loss of control as problematic because it is a part of a mechanism that most/ normal speakers have control over. They also have control over the mechanism on occasion. Given the underlying assumption that we should be in control of how we speak and that we should have a sense of certainty in everyday interaction, the erratic nature of stuttering as something that "just happens" creates distress. The scenario of "my body (speech) let me down when it matters most" is commonplace. Stuttering varies, is unpredictable and disruptive in contexts of communication where maintaining order is assumed thereby generating suffering.

Extended moments and tiring communication

The stuttering event can be described in four phases. The before, during, after moment of stutter, as is traditional in the literature. I have added here the extended moment as a context that generates suffering noting that suffering also appears before during and after the stutter. The extended moment I refer to here occurs after the block/struggle. Hennie and Gareth tell of attempts to recover after the "fall" (moment of struggle) which also generates suffering as they try repeatedly and often fail to achieve their status as "normal fluent" speakers. This struggle persists in the

face of extended uncertainty because there is no guarantee that the stutter will not appear. Hence, the struggle continues after the block. However, these extended moments collide with what follows in the conversation as new struggles emerge providing an impression of the extended, spiraling and pervasive nature of the struggle. It also provides an impression of being unable to “feel in control” over extended periods which does not qualify or feel like “normal” The entire conversation could become tiring and tiresome for both speaker and listener with Thando, Hennie and Gareth telling of feeling physically exhausted when they persist with conversations with great struggle over extended periods creating a context for suffering.

Communication in jeopardy

Participants tell of suffering generated from their role in disrupting communication. In each story participants tell of disruptions of communication in the presence of communication partners. How and why does a stuttering result in a communication problem and how does this generate suffering?

Temporal disruption

Stalling information: When the block/struggle occurs there is recognition that “something wrong” has occurred. They know what to say but struggle to say it within a normative time frame. Verbal communication in general is rapid with words flowing at a typical rate 160-220 syllables per minute. All participants tell of a blocks which last variably from 1 to 60 seconds or longer. Thando tells of disability as a block may extend up to two minutes. Hennie and Gareth tell of similar lengthy disruptions. Speech flow rate falls outside the normative expectation. As a consequence, information flow is impeded, there is loss of listener attention, breaks in patterns of turn-taking while the listener fills in the words. Conversations maybe inappropriately terminated by the speaker or listener.

Content Agitation

Approximations: As the struggle persists, messages may only be approximated as inappropriate words are selected or swapped. In an attempt to speak for shorter periods and to avoid stuttering the words chosen may not be suitable or may be incorrect. As a consequence only an approximated message may be conveyed (Hennie, Thando).

Empty communications: Participants may use too few words to convey the telegraphic messages. In addition, the feelings in the message may not be adequately captured in the communication because the emphasis may be on trying to “control the speech” or lost in the disruption (Hennie). Therefore, communication may be “content empty” and “emotion empty”

Long-winded communications: The communication may be extended inappropriately by talking around a particular subject in order to avoid using specific words (Gareth, Hennie, Thando). In addition communication becomes long-winded by inserting extraneous words and sounds.

2. AT THE SOCIAL INTERFACE

Ugly face of communication

Participants tell of the ugly face of the communication as a disruption as the struggle ensues. They tell of faces contorting and pulling, neck-jerking and “veins sticking up”, all of which constitute an ugly/abnormal face of communication. The exaggerated and sometimes grotesque facial and body movements do not assist in carrying through the intended message and is socially inappropriate and embarrassing for the speaker and the listener.

Negative emotions: Thinking-Feeling bad

The experience of suffering, generated from the sense of communication in jeopardy, includes a constellation of negative emotion. The negative emotions are pervasive and central in the story. Throughout the story of suffering fear, embarrassment, shame, frustration, anger are conveyed. The host of negative emotions occurs throughout the telling of the experience in the before, during and after phases and occurs after the stuttering event. Participants place emotions as central to the experience. I.e. “feeling bad” is combined to “thinking Bad” as participants use emotions as a basis telling about their suffering. Hennie story conveys a sense of immense frustration, despair and fear. Gareth tells of shame, fear and embarrassment. Thando conveys a sense of pervasive sense of shame and embarrassment and fear. Siyanda tells of the fear and embarrassment as a child.

Further to this participants also tell that their lack of efficient communication results in “feeling stupid” about themselves because it gives others the impression that they “do not know” and are inefficient (Hennie, Gareth Thando). Society places great value efficient oral communication as evident in school and work contexts. When there is a difficulty in achieving flowing and optimum communication, there is a sense that one is “stupid” or “doesn’t know”.

From personal experiences with stuttering participants tells that their suffering is generated from being “out of control” when speaking, lacking the ability to participate easily and efficiently in particular conversations, the collage of negative emotions accompanying the experience generates the scenario of communication-in jeopardy.

Stuttering unfolds in face-to face interaction i.e. it occurs in the presence of a communication partner and as part of a communication event. Therefore, the social dimension is an inherent part of the experience embedded in the story. Here I consider the social conditions that shape identity as generate DisOther in relation to stuttering.

Odd-one out with a problem

All participants tell of feeling different to others, of feeling “odd” compared with people in their immediate contexts. The feeling of being odd during communication relates to the visibility-concealability factor. Stuttering is easily recognised as it is generally visible, often difficult to conceal and manifests in face-to face interaction in everyday conversations. Hennie captures the essence of this when he tells of feeling “different to the rest of the nation”. However, difference in itself does not create suffering. The difference is based on a negative, deficit evaluation - on what one can’t do in relation to others in society. This deficit orientation is a prevalent societal orientation. Although competing discourses about whether people in society perceive stuttering as a problem or not emerge in the stories, dominant among them is that stuttering is

a recognised problem by lay people and professionals. In all stories stuttering is regarded as a problem in school, home and work contexts. The “medicalising” of stuttering (Gareth, Hennie, Thando) reflects that society considers stuttering as a problem to be treated/ corrected and has an infrastructure to do so. Casting stuttering as a problem, disorder, disability is borne of a broader social environment where participants discover through others that stuttering is a problem- not just difference. The realisation of stuttering as a stigmatised phenomenon occurs via Powerful Others (significant members in their lives)

In Gareth’s story there is concern about his stuttering by parents, nurses, teachers up to high school. The concern continues in University and work contexts by those who notice and describe him as a stutterer. Hennie’s is aware of stuttering as a difference but official diagnosis occurs at school and upon his referral to the therapist. The casting of stuttering as a medical problem is implied as Hennie pursues speech therapy to treat the disorder. In Thando’s story there is also a diagnosis and concern by teachers in primary school and they discuss their concerns with his parents. A formal diagnosis is confirmed when he gets to University and attends speech therapy. Siyanda discovers stuttering as problematic in the school context. In all stories the “stranger” also features as a Powerful Other because the stutter is overt, obvious and therefore easily identified by anyone.

Included in the cohort of Powerful Others are peers and schoolmates who tease thereby reinforcing the stigmatised nature of stuttering. Thando and Siyanda tell of teasing in Primary School. Hennie tells of teasing by his friends in high school .He does not consider the teasing negative in a derogatory sense but it does draw attention to his stuttering. Teasing emerges as intentional provocation with comment on the disfluency as the target of the tease and serves to highlight a norm deviation in a public way. Teasing is initiated by groups who have greater social power than the individual/s being teased. Stuttering emerges then not only as a personal problem but as one society has jointly constructed as a problem. Suffering is generated when through a variety of social processes participants discover they have a problem that is stigmatised.

Burdening Relationships

Stuttering is disruptive and has potential to hinder or strain the interpersonal relationship. Thando, Hennie, Gareth tell of the strain and embarrassment of listener. Because disruptive struggle occurs at the interface of a communicative relationship it has potential to cause alienation of communication partners. As the struggle ensues, the listener is lost are long and overlaid with other sounds not part of the message. The listener may not understand the message due to compromised intelligibility and makes requests for repetition of message. The listener must expend extra time and energy listening to the conversation, may lose interest, end the conversation or complete the utterance incorrectly. The listener may also feel embarrassed and cut off contact and judge the speaker severely. Moreover, the listener judges the speaker as “not knowing” or “stupid”. Suffering generates because of negative listener evaluations and a sense of having burdened and threatened the relationship. This scenario unfolds in multiple relationships over time compounding suffering.

A puzzling problem

Participants describe stuttering as a condition that defies understanding. It presents as a puzzling scenario for society and themselves. Not knowing what stuttering is –

like measles or a broken leg- allows the problem to become further mystified as different arms of society talk about it in different ways. The sense of never knowing what the problem is also generates suffering because the possibility of getting rid of stuttering problem becomes more unlikely, and reinforced over time. Participants know few or no other people who stutter –especially as children. There is a sense that they are different and no one or very few others in their immediate context has this problem (Thando, Gareth). As a consequence they are unable to compare or share their difficulties giving the impression of suffering generated from “being alone” with this problem.

Chronic and persisting nature of stuttering

Participants tell of the chronic nature of stuttering as an aspect contributing to suffering. All participants tell of the appearance of the symptoms at an early age and of their understanding as being different during the early primary school years. The phenomenon persists over their life courses and although their stuttering is not necessarily consistent and uniform it is a condition they must negotiate as a daily part of their lives. Unlike many chronic conditions like multiple sclerosis, stroke where there is a later onset in adulthood, stuttering occurs early on in life and creates potential for suffering to be experienced early on in life and to persist over time. Suffering is also generated from realisations that despite the many attempts at alleviation (Hennie and Gareth) and the advice from others “that it will go away” (Thando), it remains throughout adulthood. All stories tell of the phenomenon as “It’s always there” referring to its persisting, unrelenting nature. By contrast if stuttering were a short-term, once off event the impact would not be as significant. In Figure 2, the trajectory of suffering, the chronic, persisting nature of the stuttering and the associated experience of suffering is evident.

DisOthering is generated from having a phenomenon that is obvious, chronic, persisting, seemingly unresolvable resulting in a “normative-performative” communicative failing.

SUMMARY : The experience can be described as a throughfare in which the bodily, personal, self and society interact continuously to produce the experience of being DisOther